

**MEETING SUMMARY  
PRESIDENT'S CANCER PANEL  
STRATEGIES FOR MAXIMIZING THE NATION'S  
INVESTMENT IN CANCER**

December 3, 2007  
San Juan, PR

**OVERVIEW**

This meeting was the third 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

Margaret Kripke, Ph.D.

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

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

***Roundtable Participants***

Peter Bach, M.D., M.A.P.P., Associate Attending Physician, Health Outcomes Research Group,  
Memorial Sloan-Kettering Cancer Center

James Doroshov, M.D., Director, Division of Cancer Treatment and Diagnosis, NCI

Lloyd Everson, M.D., Vice Chairman, US Oncology

Elmer Huerta, M.D., M.P.H., Founder and Director, Cancer Preventorium, Washington Cancer  
Institute and President, American Cancer Society

Paula Kim, President and Founder, Translating Research Across Communities

Beverly Laird, Ph.D., Vice Chair, Director's Consumer Liaison Group, NCI

Clifton Leaf, M.F.A., Journalist; Member, Board of Directors, Susan G. Komen for the Cure

Reynold López-Enríquez, M.D., Interim Director, University of Puerto Rico Comprehensive  
Cancer Center

David Nathan, M.D., President Emeritus, Dana-Farber Cancer Institute

Lee Newcomer, M.D., Senior Vice President, Oncology, United Healthcare

Craig Thompson, M.D., Director, Abramson Cancer Center, University of Pennsylvania

**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 treatment, to palliation in the final stages of the disease. The second objective was to develop recommendations on how to achieve needed changes and who should effect 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 important opportunities for immediate action; the third focused on truth telling in the cancer enterprise; and the fourth focused on applying business models to the cancer enterprise.

### ***Dr. Lloyd Everson***

- v Dr. Everson is Vice Chairman of US Oncology, a health care services network dedicated exclusively to cancer treatment and research. US Oncology's position is that to survive economically and continue advocating for patients, doctors must stop complaining and make an effort to effect needed changes in the current health care system.
- v The current system focuses on treatment for diagnosed disease. In order to effect change in the entire cancer care paradigm, there must be a shift to the areas of prevention and early detection. This change must include reassessing the reimbursement structure for such services so that providers can continue to function financially while at the same time give attention to prevention and early detection. Similar changes must also be made in the clinical trials realm; without incentives, providers will not participate in clinical research.

### ***Dr. Beverly Laird***

- v Although Dr. Laird's professional background is in public health and patient advocacy, she is also a cancer patient undergoing treatment. As Vice Chair of the NCI Director's Consumer Liaison Group (DCLG), Dr. Laird is tasked with advising how patient advocates can be integrated within every level of NCI.
- v The research effort should be hastened whenever possible in order to benefit current, as well as future, patients. In the meantime, retrospective observational research can provide insight into the varying outcomes experienced by patients undergoing the same treatments. Individualized treatment begins with individual patients.

### ***Dr. Elmer Huerta***

- v After spending many years as a medical oncologist, Dr. Huerta founded the Cancer Preventorium, which has seen almost 22,000 people in the past 12 years, 85 percent of whom have no symptoms. Located at the Washington Cancer Institute in Washington, DC, the Preventorium provides screening, information, and navigation services to low-income residents. Dr. Huerta also hosts various Spanish-language radio and television programs aimed at disseminating health information to the public.
- v The medical community should apply what is already known about cancer detection and prevention.
- v When people are provided with information sensitive to their needs, backgrounds, and cultures, they listen to and act upon that information. Public education about prevention and

detection is extremely important in reducing cancer incidence and mortality, and the media can and should be used to that end.

**Mr. Clifton Leaf**

- v Mr. Leaf is a journalist and member of the Susan G. Komen for the Cure Board of Directors.
- v Even though public response to coverage of health care issues is positive, media resistance to publishing prominent articles on health care issues persists.
- v Incentives should be aligned with the goal of translating knowledge into action instead of aligning only with financial and prestige-related goals (e.g., publishing journal articles or participating in study sections).

**Dr. Craig Thompson**

- v Dr. Thompson is Director of the Abramson Cancer Center at the University of Pennsylvania.
- v Cancer is not an instantaneous, acute disease to be treated as an emergency, but an indolent, progressive disease that should be attacked in its premetastatic state. Research into how and why cancer progresses can help change perspectives about diagnosis and treatment.

**Dr. James Doroshov**

- v Dr. Doroshov is the Director of NCI's Division of Cancer Treatment and Diagnosis.
- v Too often, government agencies cannot effectively work together or share information due to regulatory, intellectual property, and other legislative and legal concerns. NCI, the Food and Drug Administration (FDA), and the Centers for Medicare and Medicaid Services (CMS) have attempted to work together to facilitate basic and clinical research, but funding and operational barriers limit their ability to cooperate and collaborate. For example, a current NCI biomarker validation trial in lung cancer could eventually save CMS hundreds of millions of dollars based on new, personalized approaches to treatment, but there is no mechanism through which CMS can help expedite this trial. If cooperation and information sharing were easier, it would accelerate the application of research findings to benefit cancer patients.

**Dr. Peter Bach**

- v Dr. Bach is an Associate Attending Physician with the Health Outcomes Research Group at Memorial Sloan-Kettering Cancer Center. He has also served as a senior advisor on cancer policy at CMS.
- v The most effective change to make in the current cancer enterprise would be dissemination and delivery of information already known. The vast majority of Federal research funding is dedicated to new discovery, while very little is spent on research aimed at delivery. As a result, patient care is less individualized and moving at a slower rate than it should be.

**Dr. Reynold López-Enríquez**

- v Dr. López-Enríquez is a surgical oncologist and Interim Director of the University of Puerto Rico Comprehensive Cancer Center. He has also served on the American College of Surgeons Commission on Cancer and the American Cancer Society (ACS) National Board of Directors.
- v Educating the current and future professional populations is the most important tool for the cancer enterprise. There are no courses that provide an overarching education about cancer. While programs in medical oncology, surgery, etc., provide pieces of the overall picture, the entire spectrum of cancer is not covered. If specific questions about cancer were added to the medical board exams, medical schools would be forced to respond with a changed

curriculum. Likewise, high school curricula can be influenced by a few additional questions on the SAT and other national exams.

- v The research community could take advantage of the vaccine requirement for school children by also requiring a DNA sample for future use.
- v Labeling some groups as minorities may discourage them from listening to a “majority” message about early detection.

**Dr. Lee Newcomer**

- v Dr. Newcomer is a medical oncologist who currently directs the Oncology Division for United Healthcare, which uses a \$2 billion budget to care for approximately 111,000 patients in active therapy. Dr. Newcomer also serves as Chair of the Board of Directors of Park Nicollet Health Systems, a 650-physician multispecialty group. Park Nicollet’s 400-bed hospital has used an integrated electronic medical records system for the past 8 years.
- v The cancer research enterprise needs consistency and transparency in treatment regimens, testing, and record keeping. Standardization of testing (e.g., HER2 testing) could protect patients from unnecessary treatments, as well as encourage database registration that is comparable across institutions. Often, registry information is confidential, and a treatment’s effectiveness cannot be confirmed outside of that institution. Patients would be better served if the medical community standardized care using the knowledge currently available, applied it consistently, and made the results publicly available so that physicians could make informed decisions.
- v Many physicians within an institution resist standardization, fearing it will compromise their independence. However, standardization works to show whether and how treatments succeed or fail. About 40 percent of current spending could be saved through standardization and transparency in treatment regimens and record keeping.

**Ms. Paula Kim**

- v Ms. Kim is the President and Founder of Translating Research Across Communities.
- v The medical community searches for the perfect test or the perfect treatment, which results in a very slow process of adoption of new knowledge. Sometimes, incomplete knowledge is sufficient to support changes in prevention, screening, and treatment practices. The cancer community should accept uncertainty and apply available “good enough” knowledge while research continues.
- v NIH should pay more attention to the business aspects of cancer research. The impact of high indirect costs on the amount of research that can be conducted through NIH funding is an important issue.
- v The cancer research enterprise should be reengineered with a more patient-centered focus.

**Dr. David Nathan**

- v Dr. Nathan is President Emeritus of the Dana Farber Cancer Institute, Robert A. Stranahan Distinguished Professor of Pediatrics and Professor of Medicine at Harvard Medical School, and author of *The Cancer Treatment Revolution*.
- v While the medical care system in the United States is broken, there have still been triumphs in cancer care. Smart drugs will change the way cancer is approached, moving from organ-based diagnosis to gene-based diagnosis. In order to take full advantage of this opportunity, imaging technologies and combination drug treatments must be emphasized.
- v The most effective cancer prevention interventions available for immediate application are controls on tobacco and estrogen.

## **ROUNDTABLE DISCUSSION: DEVELOPING A VISION FOR THE FUTURE OF THE CANCER ENTERPRISE**

- v The ideal system is efficient, transparent, and patient-focused, employing consistent treatments and fully integrated electronic systems, which can then provide measurable outcomes.
- v Research innovation in cancer centers should not be stifled, but must be balanced with delivery of transparent, patient-focused, and measurable high-quality health care.
- v While there have been advances in community cancer care, as illustrated by the operation of many new community cancer centers, standards for care in such centers have not been established. Currently, any organization can deem itself a cancer center, and there is no way for a patient (or provider) to assess the quality of care in community cancer centers. The American College of Surgeons has formed the National Accreditation Program for Breast Centers in the hope that accreditation will help patients and providers make informed decisions about treatment and care.
- v Patients have become less afraid to come in for screening, but more can be done to empower them to make medical choices. For instance, more education on clinical trials access should be made available to them. The system should provide strong incentives for providers to discuss these options with patients, as well as physician and medical student education on these topics.
- v Consistency of messages across all involved organizations and institutions, governmental and nongovernmental, is imperative. Standardization of treatment based on current knowledge will help achieve this goal.
- v The network of cancer centers, from regional to community, must be strengthened and centralized, using a logical business model. The patient should be made aware when another center has more experience or better success rates than his or her current treatment site. Incentives used to encourage the physician or patient to use the more experienced center would increase referrals and improve outcomes. For instance, the cost for using a low-volume surgeon (volume refers to the number of surgeries performed) could be 20 percent higher than for a high-volume surgeon. In many cases, community oncologists do not refer patients to high-volume centers because they do not want to lose income from that patient. Most physicians do not have the information needed to make an informed referral and do not have time to research such information.
- v Nurses provide a significant amount of care delivery, but the system to train and support nurses is broken. Currently, nursing schools do not pay professors enough to allow the recruitment or retention of faculty. As a result, the nursing industry faces a significant shortage, which will impact cancer care.
- v The system needs an investment in tertiary and quaternary health care, which is health care beyond the state of the art. In one imagined system, health insurers will not reimburse unless predefined protocols are followed. Such incentive plans, however, overlook the fact that one size does not fit all diseases or all patients.
- v No patient's data should go wasted; every clinical act should contribute to medical knowledge.
- v Information must be easier for patients to access and understand. For instance, 1-800-4-CANCER and [clinicaltrials.gov](http://clinicaltrials.gov) offer a wealth of information, but no next steps are planned to understand the information, its general relevance, its specific relevance to the situation, and how to act on it. These information sources should be translational as well as informational.

- v Community oncology groups cannot afford to implement many of the suggestions that result from PCP meetings because the overhead costs are too great. Individual oncologists will eventually be forced into group practices, and small groups will be forced to join larger groups.
- v The fragmentation that makes the implementation of PCP recommendations difficult in a physician practice also exists in government policy programs.
- v The ideal cancer health care system would prevent what can be prevented now, detect early what can be detected now, cure what can be cured now, and discover through research new ways to prevent, detect, and treat cancer.
- v The present system values certainty over possibility, based on current knowledge. Instead of polling 1,000 colon cancer experts, for instance, on whether a particular therapy makes sense in their experience, the present system insists on many years, many patients, and significant cost to arrive at the same answers—which are rarely definitive. The idea that this research process will result in certainty holds back good science. An alternative is to follow a different culture: university-incubated information technology. That culture values breaking rules, speed, and information sharing—without licensing each individual piece of intellectual property or one large piece to a single developer with the power to raise prices. Medicine and health care must be treated as if they were entrepreneurial enterprises.

## **ROUNDTABLE DISCUSSION: OPPORTUNITIES FOR IMMEDIATE ACTION**

### **Obstacles**

- v Because the enormous potential benefit to patients from new research being conducted is not emphasized, there is no national incentive to incur the costs necessary to translate that research or change the cancer care system. The public, political leadership, and health care providers must recognize the great promise of new scientific knowledge in order to make the massive changes to the delivery system that are needed to incorporate that knowledge.
- v Too many incentives in health care delivery are based on financial or career-related self-interest on the part of providers. Incentives should focus on patients. The only incentives that should be taken into consideration in changing the system are the prevention, detection, and treatment of cancer.
- v The system's extreme focus on treatment overlooks the promise of prevention and early detection. Seventy-five percent of cancers can be either prevented or detected earlier, but the health care system is not prepared to work as a health-promotion and disease-prevention system.
- v There is no honest communication about the human and financial cost of cancer and, thus, no urgency to fight it. Likewise, rapid communication about risk factors is not being utilized to educate the public.
- v There is, in fact, no system within which to work for change. The thousands of practices, clinics, and providers treating cancer patients do not cooperate—they compete. This fragmentation means that change benefits some and damages others.
- v A lack of standardized, measurable outcomes of health care prevents any fundamental measurement of success.
- v Intellectual property issues and a culture that discourages sharing impede data collection and use. A lack of resources to collect, pool, and make data available hinders research efforts.
- v A large investment is being made in cancer care, but there is no agreement on a system of metrics (e.g., health care outcomes, morbidity and mortality rates) that could be used to

measure the return on that investment. Some people argue that measurement of return on investment is not an appropriate way to look at the investment in health care because society is willing to spend at least some money on care even when no economic return can be expected.

- v The medical and research communities are reluctant to publish the results of research studies that do not prove their hypotheses, thereby ensuring that the cancer research enterprise does not learn from negative findings.
- v Advocacy groups that have funds available to support cancer research do not have information on potential grantees because government agencies do not provide them with access to grant applications that have scientific merit but do not receive funding due to limited resources. Applicants must find alternate funding sources on their own.

## **Recommendations**

- v Public concerns about safety result in low enrollment in clinical trials and have led to increased risk avoidance on the part of the FDA. One result of this trend is fast-track approval of a drug after Phase II/III trials, followed by safety surveillance in Phase IV trials.
- v Congress should be asked to mandate that every drug receiving fast-track approval following Phase II/Phase III trials be made available only through Phase IV clinical trials. This would boost enrollment in trials because it would eliminate off-label use—patients who want the drug would only have access through trial participation. A Congressionally mandated 5-year extension of patent protection would encourage buy-in on the part of pharmaceutical companies.
- v Mandating of Phase IV trials for drugs approved through the fast-track process would require significant financial infrastructure to support the clinical trials apparatus. Further extending patent life would keep drug prices elevated for a longer period of time. These issues call into question whether this proposed strategy would accomplish overall economic gains.
- v Pharmaceutical companies charge high prices for drugs to recoup the significant investment in 6 to 8 years of clinical trials required for FDA approval. Enrolling more people in trials raises the costs and, thus, the price of the drug. This part of the system must be reengineered to increase value and decrease the timeline.
- v The current clinical trials system, begun 50 years ago, is no longer appropriate. The timeline for mounting and conducting a clinical trial is far too long; it must be shortened in order to create a rational system of prioritization and efficiency. To shorten the clinical trials process, the patient selection process must first be improved. Genetic research should be used to select patients and imaging science should be used to determine patient response. Trials need to be organized by mechanisms and pathways that drive cancer rather than by organs and cancer sites.
- v In order to effect change, major stakeholders in the cancer enterprise—pharmaceutical companies, payers, patients, the research community, etc.—must form an alliance and produce a national agenda to present to Congress.
- v Researchers should rethink how to link available data sets and expand access to clinical trials at the community level. For example, claims information, coupled with trial data, offers a faster path to identifying toxicities (months), as opposed to standard physician reporting (years).
- v NCI-designated Cancer Centers should develop stronger outreach and public education programs. Reduction of advanced-stage cancers and tobacco-related cancers in their communities would serve as outcome measures for these efforts.

- v The Internet can be an important tool to reach the community, but costs are high and funders do not always recognize its value. For instance, the Abramson Cancer Center's Web site, OncoLink, which has 3,000 cancer survivors enrolled, costs \$1 million per year to maintain. However, NCI does not consider the site part of the Center's commitment. The value of technology, such as the Internet, should be codified in some way.
- v Grant review criteria should be revised to give investigators credit for experience in areas such as survivorship and prevention and require applicants to document outreach strategies and relationships with community organizations.
- v Because CDC, not NCI, is responsible for public health and health education programs, partnerships with and among various Department of Health and Human Services (DHHS) agencies and outside organizations would enhance education and information dissemination, which would benefit the overall cancer enterprise.
- v The Department of Defense's Congressionally Directed Medical Research Programs (CDMRP) fund important projects without the complications and obstacles involved in traditional NIH funding mechanisms. This could serve as a model for NIH cancer research programs.
- v Partnerships between the advocacy/philanthropic communities and cancer centers should be created to help centers fulfill their unfunded mandate to implement outreach programs. The greatest impact of cancer center outreach programs occurs with the cooperation of the local communities, which include philanthropic organizations, physicians in practice, and nurses. Centralized authority does not have the same impact.
- v NCI can play a key role in gathering stakeholders together to create a plan for the future. Convening these sessions with an advocacy group as a co-sponsor will lend credibility to the planning process and push participants to work together. Another important stakeholder is the ACS, which consumers rely upon as a trusted source of information.
- v More should be done to encourage non-health care companies to participate in prevention and early detection, perhaps through employee programs. The C-Change CEO Roundtable on Cancer has begun this work, through the CEO Gold Standard, but many more companies need to become involved.
- v Researchers and policy makers should be careful when using economic arguments (i.e., financial savings) as an incentive to support programs, as living longer uses more resources than dying sooner.
- v Professional societies (e.g., American Society of Clinical Oncology, American Association for Cancer Research, Oncology Nursing Society) that have extensive educational resources should be included as partners in developing public education messages about cancer prevention and early detection.
- v US Oncology is currently evaluating a standardized approach to cancer care delivery in several major cancers. Every patient receiving the standardized approach is compared with a clinically matched patient treated in the community. By the end of spring 2008, US Oncology will have enough data to begin analysis. If the standardized approach proves optimal, the group will shift its reward system to reflect a preference for that approach. CMS conducted a similar program in 2006, adding new Medicare billing codes that documented stage/extent of disease and whether accepted practice guidelines were followed. Linking payment to standardized protocols can be established at multiple levels in a coordinated fashion without inhibiting competition in health care delivery.
- v Every oncology group should discuss treatment approaches for major cancers to assess and create internal consistency; they should then document these approaches. A mechanism to



register outcomes for comparison among the groups would illuminate performances in the different groups.

- v NCI should establish a communication system to disseminate information about standardized, evidence-based protocols to the cancer care community, including providers, patients, and advocates.
- v Clinical trials should be allowed to be unblinded, which would create greater transparency and efficiency. In an unblinded trial, if the investigator notices an overwhelming negative reaction, he or she can make more efficient, informed decisions about the future of the trial.
- v If a standardized approach to delivering cancer care is shown to be superior to the current, decentralized approach, the entire incentive system must be changed. Physicians would need to be paid on the basis of disease condition management, with minimal fees for services; this would provide a large sum of money for taking care of the patient according to defined protocols.
- v In order to create a comprehensive network for funding biomarker research, the research community must have access to high-quality specimens that have been validated with pathology. Information about how the specimens were collected, how they were preserved, what kind of anesthesia was used, etc., must also be available in a format that is conducive to facilitating genomic and proteomic analysis.
- v The research community is in dire need of a matchmaking system that will match patients to clinical trials to providers to specimen repositories. For example, if a researcher needs a pancreatic tumor specimen with certain mutations, there is no central or comprehensive search system for finding it. Unfortunately, the most valued biospecimens are controlled. There must also be a system to capture specimens from the 1.4 million Americans newly diagnosed with cancer each year.
- v Venture capital could be another source of funding for physicians/researchers who can successfully develop both a research plan and a business plan for innovations in oncology service delivery.
- v The term *oncology providers*, as opposed to *oncology physicians*, should be used to better capture the wide range of professionals who care for patients.
- v Medical schools, and specifically medical school deans, should be involved in the process of redesigning the cancer care enterprise.

## **PUBLIC COMMENT**

There was no comment from members of the public.

## **ROUNDTABLE DISCUSSION: TRUTH-TELLING IN THE CANCER ENTERPRISE**

- v Clinical studies lack adequate numbers of participants, and many patients who do participate are enrolled in low-value trials.
- v Messages that emphasize the fact that clinical trials might result in dramatic breakthroughs that can save people's lives may be working against efforts to raise participation rates. Most Americans know that there is only a small chance of enrolling in a trial for a breakthrough medication and, therefore, do not enroll.
- v The message that advances are more likely to be achieved through incremental steps than through dramatic breakthroughs is not communicated to the public. Also, the pressure to

accomplish dramatic advances sometimes leads researchers to misidentify incremental steps as breakthroughs.

- v The cancer care community does not advertise its successes effectively, if at all. There have been tremendous gains in understanding and treating cancer in the past 50 years—gains that are not always communicated to the public.
- v Many decreases in cancer mortality are, in fact, attributable to earlier detection, not new medicines. In breast cancer, approximately half of the gains in survival over the last 30 years have been from early detection and half from treatment. Most of the reduction in colon cancer deaths has resulted from increased screening.
- v A lack of candor on the part of providers about realistic outcomes of clinical trial participation creates patient distrust in the medical establishment. When a protocol is not successful, the patient blames the provider for not “telling the truth” and passes that opinion on to friends and family. Some study results also oversell the benefits of a treatment, claiming to extend life substantially when, in fact, the extension is likely to be brief.
- v Medicine is not as accurate as commonly believed. The Beth and Glenn Rand Study, published in *The New England Journal of Medicine*, discovered that patients receive evidence-based recommendations only about 50 percent of the time; 11 percent of the time the recommendation is, in fact, harmful.
- v Evidence is not always enough to persuade the medical community to adopt change that is uncomfortable or does not fit current paradigms. For example, even though a study of adjuvant Trastuzumab showed that patients responded in the same way whether the treatment lasted nine cycles or 1 year, many providers in the United States still insist on giving 1-year treatments.
- v The idea that pharmaceutical companies encounter difficulties because of the high costs of clinical trials is a myth: these companies have the highest operating margins of all companies on Wall Street, with approximately 20- to 25-percent profit margins.
- v Many low-value clinical trials are conducted in response to cultural imperatives. The industry rewards pharmaceutical companies for developing “new” drugs that are only slightly different from their predecessors. Likewise, the academic environment demands a certain number of authored publications for promotion or tenure. The “truths” of these cultures are not communicated to the public.
- v Some physicians do not refer their patients to clinical trials out of fear of losing income, which neither promotes candor about appropriate cancer treatment nor furthers the cancer clinical research effort.
- v Patients interested in clinical trials must understand where they fall in the spectrum of treatable cancers. End-of-life care is more appropriate for the elderly patient with metastatic lung cancer, whereas trial participation may be appropriate for a younger patient who may benefit from interventions to treat early-stage lung cancer.
- v Patients often view clinical trials as research studies rather than opportunities to receive the latest validated cancer treatment.
- v The language of survivorship does not communicate the reality of cancer. Currently, 5 years is considered “long-term survivorship,” but reports on increases in long-term survivorship do not reflect that fact. Also, significant drop-offs in survival rates between 5 and 10 years are not reported.
- v Messages delivered to the public about cancer are fragmented, inconsistent, and public relations based, rather than science based, and tend to be centered on treatment instead of health promotion or disease prevention. Few journalists know how to communicate health

issues or have a global understanding of the cancer care enterprise. A new national cancer education program, using varied media outlets and providing consistent, science-based messages, could help educate the public and providers.

- v The research culture, in general, does not value creation of new knowledge for its own sake, forcing researchers to package general advances as specific, disease-related gains in order to ensure funding and/or publication, without any intention of having an impact on cancer.
- v One of the faults of the peer-review system is that true peers do not conduct the reviews. Reviewers are seldom experts in the subspecialties presented to them and, therefore, do not always recognize good science.
- v The public is not informed about how little the cancer research community supports resource sharing, particularly biospecimen sharing. It would be helpful to conduct an audit of processes used by biorepositories to review and fulfill specimen requests and communicate those results to the patient community.
- v Lack of information on the multitude of federally funded biorepositories is a barrier to information sharing. NCI has invested millions of dollars in biospecimens and biorepositories but only recently began collecting comprehensive information on these resources. An inventory of NCI-supported repositories has been conducted, but there is no national database of biospecimen resources or of clinical trials that are collecting specimens.
- v The way NIH codes and reports its spending is inefficient.

## **ROUNDTABLE DISCUSSION: BUSINESS MODELS IN THE CANCER ENTERPRISE**

- v Viewing the cancer enterprise in the context of four traditional business areas was suggested: research and development (e.g., basic research); manufacturing (e.g., translational research, clinical trials); sales and marketing (e.g., public and provider education); and delivery (e.g., information dissemination, access to care).
- v In the cancer enterprise, as in business, if any one of these four components fails, success is compromised.
- v Participants were asked to determine responsible parties within each area, identify problems, and suggest solutions to those problems.

### **Overarching Issues**

- v No one is held accountable for evaluating research investment and its impact on the cancer enterprise as a whole.
- v NCI's focus should be in basic and clinical/translational research, not in education and delivery. A separate national cancer education program would manage educational issues and allow NCI to focus on the areas where it has made significant progress. However, it can and should conduct research on prevention and health care delivery.
- v The current funding crisis severely restricts how much research can be conducted by young investigators who have been recruited and trained with great effort and expense. This will result in the loss of a significant portion of the next generation of clinical and basic researchers.

### **Basic Research**

- v There is pressure to conform to popular thought, as opposed to reaching for breakthrough science.
- v Because industry funding influences topics addressed in basic research, knowledge generated by individual laboratories becomes separated into disconnected parcels of intellectual

property. This is particularly troublesome when multiple parties, including Federal and state agencies, private individuals, etc., have funded the research.

- v Basic science and clinical science should be separately funded enterprises. Basic research, by its nature, often fails. The hope is that successful findings will make their way into the delivery system. In this country we depend on the private sector to really translate findings into patient care.

### **Clinical and Translational Research**

- v Many prevention trials receive funding but the results are often disappointing. This is an example of how negative findings can inform further research. Imperfect information in one trial can lead to better information about a second-generation test or biomarker.
- v One speaker noted that the system for translating basic science into clinical applications works reasonably well, but the public education enterprise has largely been a failure.

### **Education**

- v The National Heart, Lung, and Blood Institute (NHLBI) has developed the National Cholesterol Education Program and the National Hypertension Education Program, both of which could serve as models for a cancer-specific education program. While these programs have been highly successful at reaching the public, some messages have been overstated (for example, the impact of cholesterol on heart disease has been overestimated by the general public).
- v Education programs should take advantage of different media channels, including radio and television, to communicate with the public. For example, Dr. Huerta produces daily radio programs aimed at the Hispanic community that summarize articles from major scientific publications at a sixth-grade literacy level.
- v Increasing public education poses issues of inundation—people receive so much information that the relative importance of each piece is lost.
- v To gain the confidence of the American people and reduce confusion, government entities such as NCI must begin telling the truth, even when that truth is negative.
- v NCI is mandated to conduct research, not educate the public. Education should be put in the hands of organizations designed to handle this task, such as CDC and the Department of Education.
- v Public education models that focus on a single disease, such as cholesterol, are difficult to adapt to cancer, which comprises multiple disease conditions.
- v Further research is needed on the impact of timing on an individual's receptiveness to messages designed to encourage health-related behavior change. Messages delivered at the appropriate point in a person's life are more likely to be effective. However, the traditional advice that people should get checkups before symptoms appear is still an important message.
- v The best approach to public education about cancer might be to focus on a single theme—that many cancers can be prevented—with assistance from marketing and public relations experts.
- v As an alternative to working with marketing experts, grassroots-level organizations and advocacy groups—which have already established trust among patients—could be valuable partners and sources of information for industry, government, cancer centers, and other organizations seeking to reach and inform cancer patients and their families. A systematic, organized approach could be used to combine the communication skills of advocacy groups with evidence-based approaches to behavior change in the development of educational programs.

- v Patient navigators, community health advisors, and outreach programs can be extremely valuable in overcoming mistrust of the medical establishment, particularly among minorities.
- v Education may persuade people to change behaviors and get screened, but there is no system to help them after screening. Underserved populations are particularly at risk for dropping out of the cancer care system. Everett Rogers' theory of innovation diffusion shows that people will take different amounts of time to adopt an innovation. Decisions should not be affected by a fear of flooding the cancer care system with too many patients.
- v The ACS is a trusted source of cancer information and should be a partner with government in cancer education efforts. For example, as science develops evidence-based prevention interventions, ACS can help in disseminating that information.

### **Delivery**

- v Today's drug pricing structure, which is based on what the market will bear, will bankrupt the health care delivery system. While some hospitals and physician groups are attempting to lower costs through competition, pharmaceutical companies operate without competition, which keeps prices high.

### **CLOSING REMARKS—ROUNDTABLE PARTICIPANTS**

- v A comprehensive diagnostic map of the cancer enterprise landscape should be generated before creating more initiatives. For instance, before expanding on cancer education, someone should be charged with analyzing what already exists.
- v The future of treatment lies in understanding that cancer is a genetic disease and each cancer is driven by abnormal genes; treatments will depend on understanding these genetic pathways and finding drugs to ameliorate abnormalities.
- v Tobacco control is extremely important to overall cancer prevention.
- v Policies should be created to shift more resources to preventive interventions that are already known to work.
- v Policies should be created to improve transparency in cancer care delivery.
- v Truth-telling issues should be addressed.
- v More emphasis on education would greatly benefit the cancer enterprise.
- v The incentive system for cancer care delivery must be changed globally. For example, financial incentives should be de-linked from volume of services for cancer providers and refocused toward prevention and early detection.
- v Incentives must be created to encourage collaboration among cancer researchers.
- v A comprehensive, consistent, multimedia, and community-based national education program could be used to educate the public on and increase the use of current cancer-related knowledge.
- v More cancer-related research could be funded through schools of public health, which focus on prevention and health behavior change.

### **PUBLIC COMMENT**

There was no comment from members of the public.

**CLOSING REMARKS—DR. LEFFALL**

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

**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 December 3, 2007, is accurate and complete.

Certified by: \_\_\_\_\_

Date: March 14, 2008

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LaSalle D. Leffall, Jr., M.D., F.A.C.S.  
Chair  
President’s Cancer Panel