

# MEETING SUMMARY PRESIDENT'S CANCER PANEL

## LIVING BEYOND CANCER: MEETING THE CHALLENGES OF OLDER ADULT SURVIVORS

January 5, 2004  
Philadelphia, PA

### OVERVIEW

The purpose of the meeting was to examine challenges of living after diagnosis and treatment of cancer for older adults (defined as those diagnosed with cancer at or after the age of 60), including access to long-term care, comorbidities, decreased physical functioning, and a variety of economic and social issues. The President's Cancer Panel (PCP, the Panel) is seeking input to help develop its recommendations to the President of the United States, the U.S. Congress, the Secretary of Health and Human Services (HHS), and the broader community of researchers, policy makers, advocates, and others.

### PARTICIPANTS

#### *President's Cancer Panel*

LaSalle D. Leffall, Jr., M.D., F.A.C.S.  
Margaret Kripke, Ph.D.

#### *National Cancer Institute*

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, PCP  
Julia Rowland, Ph.D., Director, Office of Cancer Survivorship, NCI

#### *National Institute on Aging*

Rosemary Yancik, Ph.D., Health Science Administrator

#### *U.S. Department of Health and Human Services*

Robert Zimmerman, Regional Director, Mid-Atlantic Region

#### *Speakers*

Ms. Mary Jo Albee, Community Representative, Marshalltown, Iowa  
Dr. Marilyn Brown, Community Representative, Lutz, Florida  
Dr. Mortimer Brown, Community Representative, Lutz, Florida  
Dr. Grace Butler, Community Representative, Pearland, Texas  
Ms. Barbara Hoffman, Founding Chair of the National Coalition for Cancer Survivorship (NCCS), and Professor, Rutgers Law School, Newark, New Jersey  
Dr. Warren Jones, Associate Vice Chancellor for Multicultural Affairs, University of Mississippi Medical Center, Ridgeland, Mississippi  
Dr. Michael H. Kanter, Associate Medical Director for Quality and Clinical Analysis, Kaiser Permanente, Pasadena, California  
Dr. Basil Kasimis, Chief, Section of Hematology/Oncology, Veterans Affairs New Jersey Health Care System, East Orange, New Jersey  
Dr. Sharad Mansukani, Medical Officer and Special Assistant, Centers for Medicare and Medicaid Services (CMS), Baltimore, Maryland

Dr. Anna Meadows, Professor of Pediatrics/Senior Oncologist, Children's Hospital of Philadelphia and University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania  
Dr. Richard Migliori, Chief Executive Officer, United Resource Networks, a Division of Specialty Care Services Within UnitedHealth Group, Golden Valley, Minnesota  
Dr. Carol Runowicz, Director, Oncology Signature Program and Women's Health, University of Connecticut Health Center, Farmington, Connecticut  
Mr. Jim West, Community Representative, St. Petersburg, Florida

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

On behalf of the PCP, Dr. Leffall welcomed invited participants and the public. He also provided a brief overview of the history and purpose of the Panel and the aims of the current series of meetings on survivorship. Dr. Leffall explained that this meeting would include testimony from cancer survivors, health care providers, and insurance industry representatives on the challenges faced by older adult cancer survivors and their families and caregivers, with the goal of generating ideas and recommendations for follow-up by the Panel and other stakeholders involved in reducing the burden of cancer.

Dr. Leffall conveyed the regrets of Panel member Lance Armstrong and scheduled speaker Ellen Stovall, who were unable to attend the meeting. Two cancer survivors scheduled to speak—Ms. Louise Heyneman and Ms. Katherine Stadler—were also unable to attend. Dr. Leffall acknowledged the presence of two distinguished guests: Mr. Doug Ulman, representing the NCI Director's Consumer Liaison Group (DCLG), and Mr. Robert Zimmerman, Director for the U.S. Department of Health and Human Services Mid-Atlantic Region (Region III).

## **NCI DIRECTOR'S REPORT— DR. ANDREW C. von ESCHENBACH**

### **Key Points**

- Dr. von Eschenbach noted that when he began his career in oncology over 25 years ago, survivorship was achieved by very few cancer patients, and a cancer diagnosis was thought of as a death sentence. Now, survivorship is an important part of the cancer agenda. The Panel's current series of meetings on survivorship supports efforts that focus on improving quality as well as quantity of life.
- In 1971, with the passage of the National Cancer Act, the nation made a commitment to eliminate cancer altogether, and it was believed that this could be done quickly. Over the past 30 years, it has become clear that elimination of cancer is an elusive goal. However, tremendous progress has been made in understanding cancer as a disease process and developing an infrastructure for rapidly translating new knowledge into interventions.
- The NCI has set a goal of eliminating suffering and death due to cancer by the year 2015. The nation's investment in cancer research has resulted in the potential to prevent some cancer processes from beginning, detect processes earlier, and more effectively intervene to halt or modify processes in order to change the course of disease and make it possible for people to live with, rather than die from, cancer. Survivorship is an essential part of the 2015 goal because people who live with cancer also live with the burden of long-term effects of cancer and its treatment.

## **OVERVIEW OF NCI SURVIVORSHIP PROGRAMS— DR. JULIA ROWLAND**

### **Key Points**

- Dr. Rowland, speaking on behalf of Ellen Stovall, provided a brief history of the National Coalition for Cancer Survivorship (NCCS), the nation's oldest survivor-led advocacy organization, of which Ms. Stovall is President and Chief Executive Officer. In 1995, the Coalition convened the first National Congress on Cancer Survivorship and subsequently produced a document entitled *Imperatives for Quality Cancer Care*, which called for multidisciplinary, holistic care for persons

with cancer. Ms. Stovall personally brought this document to the attention of the then Director of NCI. The result of this intervention was the establishment in 1996 of the NCI Office of Cancer Survivorship (OCS).

- The OCS adopted the NCCS definition of *survivorship* as beginning with diagnosis and continuing for the remainder of the survivor's life. The OCS expanded this concept by stating that family members of persons with cancer are also survivors. Cancer outcomes are affected by the whole network of individual, family, and community support systems.
- The OCS is an extramural program with funding authority to support research projects. Currently, the Office has more than 80 grants. Across the NIH, there are 179 FY2003 grants focusing on some aspect of survivorship.
- The OCS recently closed a Request for Applications on long-term effects among those diagnosed five years ago. The Office received 125 applications.
- Dr. Rowland expressed her appreciation for the support the OCS has received from Dr. von Eschenbach. She noted that for the first time, the NCI has a Director who is also a cancer survivor. He has promoted the issue of survivorship by identifying it as an area of public health interest in the NCI Bypass Budget.
- Dr. Rowland briefly described the cancer survivorship experiences of Ellen Stovall, whose Hodgkin's disease was diagnosed over 32 years ago. Ms. Stovall began treatment at the time President Nixon was signing the National Cancer Act into law. Those two events galvanized her into action, and she has been one of the nation's champions in advancing attention to the needs of cancer survivors. Dr. Rowland closed by stressing the deep commitment of the OCS and the NCI to listening to the testimony provided during the series of Panel meetings on survivorship.

## **SURVIVORSHIP CHALLENGES FOR OLDER ADULT SURVIVORS— DR. ROSEMARY YANCIK**

### **Background**

Dr. Yancik is a medical sociologist with special interest in cancer in older persons along the cancer control research spectrum of early detection, diagnosis, treatment, quality care, and cancer survival. The extramural perspective emphasizes major tumors that affect older persons, pharmacology of aging and cancer, clinical studies, multiple primary tumors, and quality of life. Dr. Yancik's research focuses on the impact of comorbidity on cancer treatment and care in older patients. Her NIH career began with NCI. Her current responsibilities at the National Institute on Aging (NIA) include research on aging and cancer, selected geriatric syndromes, and the promotion of NIA/NCI partnerships in initiatives at the research interface of aging and cancer.

### **Key Points**

- Dr. Yancik presented data, primarily from NCI's Surveillance, Epidemiology, and End Results (SEER) program, to illustrate the magnitude of the problem of cancer among older adults. Almost 60 percent of all cancer incidence, as well as 71 percent of all cancer deaths, occurs in the population aged 65 and older. Most major tumors primarily affect older persons.
- Expansion of the older age segment of the population alone can increase the number of incident cancers and older survivors. During the "baby boom," from 1946 to 1964, 75 million Americans were born. Increased life expectancy is also contributing to age shifts. Within the 65-and-older population,

the 85-and-older segment is projected to double from 4.3 million to 8.9 million by 2030, and 70 million Americans (1 in 5) will be 65 or older.

- Cancer does not occur in a vacuum and must be treated along with co-occurring conditions. Research has shown that cancer survivors are more likely than the general population to experience chronic conditions and limitations in activities of daily living. Comorbidity among cancer patients increases with age.
- Some of the late adverse effects of cancer treatment, especially radiation and chemotherapy in combination, can be prevented through improved dose management.
- Another issue relevant to older adults is the occurrence of secondary or multiple tumors.
- Older cancer survivors are often cared for by spouses who have their own health problems. Lay caregivers often lack the information and resources needed to deal with the variety of functional support needs of older cancer survivors.
- In January 1997, the NIA began developing priority areas for integrating aging and cancer. Many of these activities have been carried out in collaboration with the NCI. NIA priority areas relevant to the current meeting topic focus on comorbidity, previous illnesses, and disabilities in older cancer patients; multiple primary tumors; long-term survivorship; and pharmacological issues.
- In 2001, an NIA/NCI workshop was held to explore the role of NCI-designated Cancer Centers in integrating aging and cancer research; an RFA for P20 grants in this area was released in 2002, and eight projects were funded. A report from this workshop is available through the NIA Web site. Through a 2002 Program Announcement, the NIA and NCI jointly funded a group of R01 grants that are also integrating aging and cancer research.

## **DISCUSSION—DR. YANCIK**

- Masking of symptomology can serve as a barrier to cancer prevention and early detection among older adults.
- The predicted large increase in the number of cancer cases will not necessarily increase the difficulty of meeting the challenge to eliminate suffering and death due to cancer by 2015. Advances in knowledge are making it possible to change the outcomes associated with a diagnosis of cancer. Prevention of cancer is the ultimate goal, but this may take longer to accomplish.
- The NCI is addressing the expected epidemic of cancer by developing a balanced portfolio of discovery, development, and delivery efforts.
- Rapid advances in scientific knowledge place a burden on medical education to ensure that new generations of physicians are prepared to deliver quality health care.
- Cancer care is a team effort in which not only physicians but also nurses, physician assistants, social workers, therapists, and patients themselves must actively participate.
- The American Society of Clinical Oncology (ASCO) has developed a geriatric oncology curriculum, and the Hartford Foundation is collaborating with ASCO to fund fellowships in this area.
- The Oncology Nursing Society (ONS) was the first professional society to issue a position statement on cancer among older adults; this was done in 1992. The ONS actively supports the concept of comprehensive geriatric oncology teams.

- Little has been done to educate the elderly about the significant cancer risks faced by their age group. A public awareness program with tailored messages and materials is needed.
- Ageism in American society has created prejudice against participating in the specialty of gerontology.
- Cancer prevention and screening receive less attention than new developments in cancer treatment because they are not reimbursable under most health insurance.
- Increased public education is needed to explain that greater investment in health care will be needed to take full advantage of the opportunities to improve quality of life promised by new advances in cancer diagnosis and treatment.
- Use of the term *cancer epidemic* may create misperceptions and fear. Care must be taken to anticipate how information, however accurate, will be assimilated by the public.
- The “team” addressing the cancer problem includes not only doctors, scientists, and patients, but also people who do not have cancer, because they are being asked to help pay for a very expensive program to reduce suffering and death due to cancer. Public education efforts should include an explanation of the value of this investment for society as a whole.
- Clinical trials focusing on quality of life do not receive the same attention as intervention trials.
- Recently, the SEER program has increased sampling from ethnic minority and low socioeconomic status populations, and efforts have been directed toward better integrating SEER with registries supported by the Centers for Disease Control and Prevention (CDC). These efforts have enhanced the ability to use SEER data in discussing cancer-related health disparities.

## **STORIES FROM SURVIVORS—GROUP I**

### **Presenters**

**Mr. Jim West**  
**Ms. Mary Jo Albee**

### **MR. JIM WEST**

#### **Background**

Mr. West was diagnosed with prostate cancer in 1997, at the age of 61, and underwent a radical prostatectomy. After obtaining a second opinion on his treatment options, he decided not to undergo radiation or chemotherapy. He felt he was not given enough information about his treatment or about support groups; he had to find that information on his own. Doctors, he thinks, should provide more information without waiting to be asked. The long-term effects of Mr. West’s cancer treatment include sexual dysfunction and incontinence. Although his experience has been that others in his community are afraid to talk about cancer, he has been determined to ignore the stigma associated with the disease and to be proactive about survivorship. Mr. West leads a local support group for cancer survivors (both men and women) sponsored by the Man to Man program of the American Cancer Society (ACS).

#### **Key Points**

- Mr. West refers to himself as a Prostate Cancer Educator. After his treatment, he felt the need to speak about prostate cancer in his community whenever he had the opportunity.

- The stigma associated with cancer remains strong. One member of the support group Mr. West coordinates, a ten-year survivor, has said that some members of his family still do not know about his cancer.
- When men ask Mr. West about the effects of prostate surgery on sexual functioning, he answers that “dead men do not have sex.”
- Some members of the medical profession fail to understand that advocates are not in competition with them. One urologist told Mr. West that he did not want his patients to attend support groups because they come back with too many questions.
- Although Florida has the second highest incidence of prostate cancer in the United States, there is no statewide education program targeting this disease.
- Prostate cancer is not just a men’s disease, but a family disease, and educational efforts should be directed at families and communities.
- Because most educational materials about prostate cancer are written at high literacy levels, Mr. West has made and distributed cassette tapes of his own speeches.
- Mr. West experienced an unusual form of job discrimination after his cancer treatment. He informed his employer that he had to make frequent visits to the restroom; as a result, he found that he was the only person among 27 working on a production line who was required to ask for permission to visit the restroom.
- Researchers who conduct clinical trials do not make enough efforts to reach out to the community, especially inner-city communities and other locations where African Americans live.

## **MS. MARY JO ALBEE**

### **Background**

Ms. Albee was diagnosed with endometrial cancer in 2002, at age 67. Due to a previous heart attack, a stress test was recommended prior to scheduling a hysterectomy. The test revealed major blockages that required triple bypass surgery. After recovering from this surgery, she underwent a hysterectomy. The surgeon removed 26 lymph nodes that proved negative. However, because the cancer was positioned near the uterine wall, she received radiation and chemotherapy through a clinical trial. Ms. Albee belongs to a support group for cancer survivors and enjoys the friendship and support she has found there.

### **Key Points**

- Ms. Albee’s support team during her cancer treatment and survivorship includes her son, sister, grandchildren, pastor, and church congregation.
- During medical checkups, Ms. Albee’s heart is monitored for potential effects of chemotherapy, but she has not received specific recommendations for long-term follow-up care or information about long-term survivorship issues.
- Ms. Albee’s doctors did not explain that the removal of lymph nodes might result in lymphedema, which she has experienced in both legs, and very little has been done to help her with the condition. Insurance does not cover the expensive compression hose recommended for her lymphedema, so she wears support hose instead.

- A nurse referred Ms. Albee to the support group she attends. The group's resource center provided her with a wig, which would not have been covered by insurance.
- Incontinence, in Ms. Albee's case, was probably caused by either radiation or chemotherapy, but no one has been willing to acknowledge responsibility.
- Although the premiums and deductibles are expensive, supplemental insurance makes it possible for Medicare recipients to survive cancer without financial disaster.
- Ms. Albee chose to participate in a clinical trial, not because she might benefit from the study itself, but because she knew she would receive high-quality care and thorough follow-up care.

## **DISCUSSION—SURVIVOR GROUP I**

### **Key Points**

- Community outreach is needed to educate the public about the benefits of clinical trials.
- The Cancer Information Service (CIS) receives many calls from older adults who need assistance in obtaining home care services, wigs, breast forms, bed pads, and other resources not covered by Medicare. Many older Americans have very limited incomes and cannot afford supplemental insurance.
- Community agencies, such as local offices of the ACS and the Leukemia and Lymphoma Society, serve as a safety net for people with cancer, especially older adults. They provide practical assistance with basic needs, such as transportation to medical appointments and housework.
- In some ethnic populations, older women decide not to be screened for cervical cancer because they believe that because they are past childbearing age, they do not need to visit a gynecologist.
- The myth persists in some communities that participation in a clinical trial involves the risk of being treated with placebos.
- People who distrust the Government are unlikely to visit the NCI Web site for information on clinical trials. Survivor-led advocacy groups should be more active in explaining the benefits of participation in trials, because their advice is more likely to be accepted.
- The Leukemia and Lymphoma Society operates a peer-to-peer telephone support program called First Connection. Newly diagnosed individuals are matched with survivors who have had similar experiences. Those interested in clinical trials are matched with survivors who have been trial participants.
- Advocacy groups could assist the Panel in obtaining input from elderly cancer patients and survivors who may not be healthy enough to attend the Panel's meetings.
- Achievements in improving outcomes for pediatric cancer patients, 90 percent of whom participate in clinical trials, have demonstrated that trials are the best way to deliver new interventions, extract information on their impact, and build on that knowledge to continually improve outcomes. However, only three percent of adults participate in trials. Enhancing participation in clinical trials is a major area of emphasis for the NCI.
- The NCI has entered into partnerships with several pharmaceutical companies to provide supplements to Cancer Centers for studies designed to identify methods of increasing participation in clinical trials by minorities, underserved populations, and older adults.



- Pediatric clinical trials have been successful in reducing long-term effects of cancer treatment by comparing standard therapies with less toxic treatments. With adults, researchers are still looking for ways to control the disease, and quality-of-life issues related to late effects of treatment are just beginning to be addressed.
- Until recently, cancer patients 65 and older have been excluded from clinical trials, even though they constitute the vast majority of people diagnosed with cancer. Increasing participation of older adults in trials will require removing perceptual barriers, such as the belief of many practitioners that older patients, especially those with comorbid conditions, are not good candidates for participation in clinical trials.
- An NCI publication called *Ways You Can Make a Difference in Cancer* provides information for cancer survivors, families, friends, and caregivers who are interested in becoming involved in advocacy activities.
- For physicians, participation in clinical research requires a great deal of effort. Informed consent and Institutional Review Board (IRB) approval must be obtained; Health Insurance Portability and Accountability Act (HIPAA) regulations must be addressed; and labor-intensive data collection and management requirements must be met. Reduced reimbursements from insurers make it difficult for most doctors to employ enough staff to participate in clinical trials.

## **STORIES FROM SURVIVORS—GROUP II**

### **Presenters**

**Dr. Mortimer Brown**

**Dr. Marilyn Brown**

**Dr. Grace Butler**

### **DRS. MORTIMER AND MARILYN BROWN**

#### **Background**

Dr. Mortimer Brown was diagnosed with colorectal cancer in 1999, at age 75. After his diagnosis, he learned through his own research that people who join support groups have a better chance of survival. Because there were no support groups in his area for colorectal cancer, he started one called the SemiColons. Surviving cancer has improved Dr. Brown's outlook on the world. Before his diagnosis, he led a very secular life, but as a survivor, he has become more focused on spiritual concerns. Dr. Brown feels that some medical personnel did not treat him as an individual with a right to conduct his own research and participate in decisions about his care. Dr. Brown is a member of the NCI's Consumer Advocates in Research and Related Activities (CARRA).

Dr. Marilyn Brown, Mortimer's wife, is an active member of the SemiColons support group. The most difficult part of the cancer experience has been learning how to help take care of her husband's colostomy. Her husband's oncologist did not provide any practical information or guidance, and the Browns did not know the right questions to ask. Their primary care physician helped them locate a nurse who taught them how to care for the colostomy at home.

## Key Points

- Being a cancer survivor has become part of Dr. Brown's identity, affecting not only his relationships with family members and others, but also the way he makes decisions on how to spend his time and energy.
- For Dr. Brown, part of the definition of *survivorship* is an obligation to give something back. He mentions the need for cancer screening to friends and students and even speaks to strangers about the risks of smoking. He uses a hat with badges from a lobbying visit to Capitol Hill as a conversation piece to help bring attention to cancer-related issues.
- Dr. Brown's only negative experience in dealing with physicians came when he was scheduled for radiation and chemotherapy, even though his oncologist had not recommended these treatments. He was not satisfied with the doctors who were preparing to deliver these treatments; they refused to discuss his concerns and simply stated that they were following the recommendations of the hospital's "cancer committee." The Browns sought a second opinion and were advised that radiation and chemotherapy were not necessary. Later, they learned that the cancer committee was composed of the two doctors who had been planning to deliver these treatments.
- Family caregivers need hands-on training to assist colostomy patients at home. Printed instructions are not adequate preparation for these tasks.

## DR. GRACE BUTLER

### Background

Dr. Butler was diagnosed with stage III colon cancer in 1999, at age 63, and was treated with surgery and chemotherapy. She felt alone and disappointed when she returned after treatment to an empty house. She joined a support group, where the most important thing she learned was how to admit she needed help and ask for it. When she had recovered physically and emotionally, she spent two years volunteering in church-related activities. Astonished to see that based on cost-related issues, many people were not being screened, she started a nonprofit organization called Hope Through Grace, Inc., to support early detection and prevention of colon cancer. Dr. Butler is a member of CARRA. She has served on a panel that worked to have March designated as National Colorectal Cancer Awareness Month and on the advisory board of the Texas Children's Hospital Cancer Center.

### Key Points

- The health care system often assumes that each patient has a support system, but this is not always true. Dr. Butler found it very painful to sit alone in waiting rooms watching other patients as they came and went accompanied by someone who provided companionship and assistance.
- Dr. Butler found it frustrating to discuss her care with her oncologist. Having read about nutrition and cancer, she asked her oncologist for advice. Instead of referring her to a nutritionist, the oncologist simply said, "Stop trying to be a perfect patient."
- After her treatment, Dr. Butler was told to come back in six months to "see if your cancer has recurred." Instead of this blunt statement, the doctors should have worked with her to develop a survivorship plan, including six-month visits to see how the plan was working. The treatment team should be replaced by a survivorship team. This team should include, at a minimum, a nutritionist, a social worker, and a family physician.

- Dr. Butler established a cancer ministry through her church and is founder of a nonprofit organization called Hope Through Grace, Inc., which is designed to promote cancer prevention among underserved and uninsured people and encourage participation in clinical trials. This organization focuses on breast, colon, prostate, and lung cancers.

## **DISCUSSION—SURVIVOR GROUP II**

### **Key Points**

- The survivorship team should include physical therapists, occupational therapists, speech pathologists, and other rehabilitation specialists, as needed. Support groups should also invite these specialists to their meetings.

## **TESTIMONY FROM PROVIDERS/INSURERS—GROUP I**

### **Presenters**

**Dr. Warren Jones**

**Dr. Anna Meadows**

**Dr. Carolyn Runowicz**

**Ms. Barbara Hoffman**

### **DR. WARREN JONES**

#### **Background**

Dr. Jones is a family physician and retired Captain in the U.S. Navy. Until recently, he served as Board Chair of the American Academy of Family Physicians (AAFP). Dr. Jones is Clinical Professor of Family Medicine, Associate Vice Chancellor for Multicultural Affairs, and Director of the Division of Multicultural Affairs at the University of Mississippi Medical Center. He is also an Assistant Professor of Family Medicine at the Howard University School of Medicine. He is Director of the Mississippi Area Health Education Centers (AHECs) and serves on the Chiropractic Advisory Committee to the U.S. Secretary of Veterans Affairs. Dr. Jones received his medical degree from the Louisiana State University School of Medicine. He is a Fellow of the AAFP—a degree awarded to family physicians for distinguished service and continuing medical education.

#### **Key Points**

- Many individuals have reported that their earliest cancer symptoms were not recognized or understood by their primary care physicians. Since patients usually have trusting relationships with their primary care providers, it is important to make sure that physicians have access to the most current information. Primary care providers are expected to know about more than 1,500 guidelines related to disease prevention, surveillance, diagnosis, treatment, and post-treatment issues; they need help in keeping up to date.
- Older patients often lack access to effective, well-informed support networks and frequently undergo cancer treatment alone. The health care system provides treatment resources but not coordinated support services. When patients see a variety of specialists, they can lose track of the detailed information their providers need to understand and meet their needs.

- Dr. Jones asked the Panel to include in its recommendations the development of a major educational program to promote the value of a “medical home,” or a usual and customary source of care, for older patients. Each patient should have a primary care provider or other health care professional who will act as a medical home for that patient and become familiar with his or her medical history. The medical home should coordinate a patient’s journey through the labyrinthine health care system and serve as an advocate to ensure that his or her needs are met.
- Translational research is needed to ensure that information about advances in long-term management for cancer survivors is available to the medical home. Dr. Jones urged cancer researchers to work closely with the Agency for Healthcare Research and Quality (AHRQ) to better operationalize basic discoveries at the clinical level.
- Dr. Jones also asked the Panel to recommend the development of a doctor-friendly electronic health record (EHR) system as an essential tool for providing successful and safe case management for all cancer survivors. Today, there are many expensive medical records systems that are not compatible with each other. A single, standardized EHR is needed to record data about consultations, laboratory tests, and other milestones in each patient’s medical history. With such a “just-in-time” decision-making support system in place, the various professionals who see a patient would not have to rely on the patient’s memory and understanding of what has happened during treatment. A summit of experts should be convened to determine the features of this system, and public-private partnerships should be created to achieve this goal.

## **DR. ANNA MEADOWS**

### **Background**

Dr. Meadows joined the faculty of the University of Pennsylvania and the staff of Children's Hospital of Philadelphia in 1974. In 1989, she became Director of the Pediatric Oncology Program. During the past year, she has begun development of a new program at the University of Pennsylvania Cancer Center for adult survivors of breast and testicular cancer. For the past 20 years, Dr. Meadows has been a member of the Lymphoma Strategy Group in the Children's Cancer Group. As Chair during the last five years, she has spearheaded new protocols for treating non-Hodgkin's lymphoma and Hodgkin's disease that have become the standard of care. Dr. Meadows has served as a member of several policy-making groups for the NIH, the University of Pennsylvania, and Children's Hospital. She now serves on the Medical Advisory Board of the Lance Armstrong Foundation and the Board of the local Leukemia and Lymphoma Society.

### **Key Points**

- Advances in pediatric oncology led the way in survivorship. Now, former childhood cancer patients are becoming adult cancer survivors.
- A survey conducted at the University of Pennsylvania’s Abramson Cancer Center found that fear of recurrence is the concern most often cited by cancer survivors. Other common concerns included prevention of second cancers, work and insurance problems, depression, weight control, musculoskeletal problems, sexual problems, and the need for doctors who understand survivors’ concerns.
- Late effects of cancer treatment include premature development of normal age-related changes, atypical presentation of common medical problems, increased risk for certain common and rare diseases, and poor response to standard treatments.

- Factors that influence late effects include age, preexisting comorbidities (both physiological and psychological), developmental stage of the survivor, and developmental stage of the family.
- For adults, late effects lead to loss of normal cells (loss of homeostatic reserve). Increased spontaneous mutations that are associated with aging increase cancer risks. Preexisting diseases and environmental exposures increase the risk of experiencing abnormal responses to earlier cancer treatment. Primary care providers need to remember that environmental risks are modifiable.
- The Abramson Cancer Center established the Living Well After Cancer (LWAC) research and clinical program to address the lack of clinical evidence concerning long-term cancer survivorship and to develop a new model of care for long-term survivors. The LWAC is supported in part by the Lance Armstrong Foundation.
- In the absence of specific guidelines for follow-up of adult cancer survivors, the LWAC program is building upon established surveillance guidelines to develop a systematic approach to the evaluation of patients. In addition to monitoring for cancer recurrence, the program creates individualized risk profiles and assesses changes in physical and personal well-being.
- For some patients, including survivors of testicular cancer and adult survivors of childhood cancer, the program uses a practice model in which each survivor is seen by a single doctor. For others, including breast cancer, a consultative model is used because patients need to be seen by multiple doctors.
- Clinical management in the LWAC program involves chart abstraction, patient questionnaires, and physical examinations. Screening and other health maintenance activities address modifiable risk factors.
- The LWAC program's research activities focus on both physiological and psychosocial aspects of survivorship. There has been little research concerning late effects of cancer and its treatment.
- Another unanswered question is where cancer survivors should receive long-term care. If this care is to be delivered in the primary care setting, educational programs will be needed to ensure that primary care physicians understand long-term risks and are knowledgeable about appropriate interventions.
- Specialized adult survivorship clinics can serve as models for delivery of similar services in the primary care setting, as well as function as a platform for conducting survivorship research.

## **DR. CAROLYN RUNOWICZ**

### **Background**

Dr. Runowicz was named Second Vice President of the ACS in November 2003. She also serves as Chair of the ACS Reduction in Cancer Incidence, Mortality, and Prevention and Early Detection Agenda Workshop. Dr. Runowicz was the first woman president of the Society of Gynecologic Oncologists. She currently serves on the NCI's Scientific Review Group and is also involved with the American College of Obstetricians and Gynecologists and the American Society of Clinical Oncology. She has been Chair of the Gynecologic Committee of the National Surgical Adjuvant Breast and Bowel Project (NSABP) since 1994. Dr. Runowicz is widely published in scholarly journals, including the *American Journal of Obstetrics and Gynecology*, *Journal of Clinical Oncology*, and *Cancer*. She has written three books on cancer-related topics: *To Be Alive: A Woman's Guide to a Full Life After Cancer*; *The Menopause Book: A Guide to Women's Health After 40*, coauthored with her husband, Sheldon Cherry, M.D.; and *Women and Cancer: A Thorough and Compassionate Resource for Patients and Their Families*.

## Key Points

- Few studies have been conducted among cancer survivors who are elderly, poor, low income, ethnically diverse, or living in rural areas. Growing older as a cancer survivor also increases one's chances of comorbidities and disabling conditions, making research in this area a challenge.
- Existing measures of quality of life and quality of survivorship, which were primarily developed in studies of pediatric cancer patients, may not be sensitive to issues unique to older patients.
- Pharmacogenomics is an emerging discipline that focuses on the influence of aging and genetics on the metabolism of drugs.
- Understanding the short- and long-term effects of cancer therapies will improve the delivery of primary care.
- Older survivors' educational needs vary depending on stage of survivorship, educational level, and type of cancer.
- Two studies being conducted by the ACS are expected to produce important information on survivorship among this population, since both focus on cancers that affect older adults.
- The Centers for Medicare and Medicaid Services (CMS) is supplying the ACS with annual health-related quality-of-life data collected from cancer survivors receiving managed care through Medicaid for statistical analysis. The ACS has found evidence that these patients had worse quality-of-life outcomes than age-matched controls.
- Several studies of breast cancer among older adults have suggested that effects on the physical domain are greater than those on social well-being. These findings can be incorporated into the design of supportive care services based on life stage at diagnosis.
- Project LEAD (Leading the Way in Exercise and Diet) is an ongoing randomized clinical trial of a diet and exercise intervention designed to improve function among breast and prostate cancer survivors. This intervention takes advantage of the "teachable moment" that coincides with the completion of treatment.
- Findings from a study of health-related quality of life among elderly female colorectal cancer survivors suggest that factors attributable to aging, body weight, and comorbidities play a more dominant role in quality of life than the initial cancer diagnosis.
- Follow-up for older adult cancer survivors may require multidisciplinary care in special clinics.
- The NCI and the NIA have a partnership to fund training programs in the emerging field of geriatric oncology.
- Cancer survivorship issues should be more widely incorporated into the collection and analysis of epidemiologic data on the burden of cancer.
- New tools are needed to standardize the functional and psychosocial evaluation of older adult survivors.
- Based on the example provided by the Childhood Cancer Survivor Study, a database of elderly cancer survivors should be established for longitudinal studies. Longitudinal studies should also be conducted to evaluate caregivers' quality of life.
- Research is needed to define age-associated factors that may exacerbate therapeutic toxicity.

## MS. BARBARA HOFFMAN

### Background

Ms. Hoffman is the Founding Chair of the National Coalition for Cancer Survivorship (NCCS). She is the author of numerous book chapters, articles, Web content, and consumer booklets on the legal rights of cancer survivors and an area specialist contributing to the *Cancer Survival Toolbox*. Ms. Hoffman is the editor of *A Cancer Survivor's Almanac: Charting Your Journey* (John Wiley & Sons [1998]), a revised and expanded version of which will be published by Wiley in March 2004. Since the early 1980s, Ms. Hoffman has advocated for the rights of cancer survivors and individuals with disabilities. She has spoken at more than 100 conferences and programs about cancer survivorship and has served as a consultant to the NCI, Comprehensive Cancer Centers, nonprofit organizations, and Web sites. She is a member of the Princeton University Alumni Schools Committee and the Editorial Board of CURE (Cancer Updates, Research, and Education). Ms. Hoffman is the recipient of the President's Award from the NCCS.

### Key Points

- Most cancer resources are directed toward medical issues, but cancer affects more than just the body. It affects the whole person, including one's ability to earn a living and achieve financial independence. Cancer survivors often have problems maintaining employment or finding new employment.
- Employment problems can lead to loss of health insurance, inability to pay for nonmedical costs related to cancer treatment (e.g., transportation), and reduced self-esteem. Survivors without health insurance have fewer treatment options, lower-quality medical care, and insufficient follow-up care.
- Employment rights for survivors have improved over the past 20 years. The Americans With Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA) provide some protection of survivors' rights. Most states also have laws that prohibit discrimination against persons with disabilities, including cancer survivors.
- The ADA covers all businesses that employ 15 or more people. The reasonable accommodations required by the Act include time off for medical treatment, flexible hours, and changes in duties to accommodate functional limitations.
- The FMLA requires employers of 50 or more people to provide up to 12 weeks of unpaid leave for workers with serious medical conditions. This time does not have to be used all at once, so a patient who requires periodic treatment sessions can take time off when it is needed.
- Even though cancer survivors have made advances in employment protection, they have not made similar progress in protecting their right to obtain and maintain health insurance. Survivors who are able to find coverage must pay prohibitively high premiums.
- Keeping track of the paperwork associated with insurance claims can be difficult for cancer survivors, who must accurately document lab reports, clinic visits, surgical procedures, and many other items to make sure they receive all of the reimbursements to which they are entitled.
- Many of the health insurance plans available to survivors limit access to health care providers; thus, survivors often must accept care from providers whose services are less convenient or appropriate than those they might otherwise choose.

- Some protection is provided by state and Federal laws. Many older cancer survivors are covered by Medicare and Medicaid. HIPAA makes it possible in some cases to transfer health insurance when changing jobs, and COBRA regulations (named for the 1986 Consolidated Omnibus Budget Reconciliation Act under which they were created) makes it possible for some workers who leave employment for medical reasons to buy into their employers' health insurance plans. The Employee Retirement Income Security Act (ERISA) prohibits employers from firing workers to avoid the cost of providing insurance for them.
- Public financial resources available to older cancer survivors include Social Security benefits, Veterans benefits, and tax deductions for medical expenses. Private resources include hospital social service departments, cancer-related organizations, pharmaceutical programs, private disability insurance, and charitable organizations.
- The two most important arenas for efforts to improve the financial outlook for cancer survivors are health insurance reform and increased advocacy and education.

## **DISCUSSION—PROVIDER/INSURER GROUP I**

### **Key Points**

- Elderly patients meet with less discrimination than in the past in terms of access to surgical procedures because anesthetics and surgical tools have greatly improved health care providers' ability to successfully treat older adults in spite of comorbidities.
- However, bias still exists in terms of cultural factors. Many researchers are unable to find ways to encourage clinical trial participation by individuals from a variety of backgrounds.
- Patients treated at major cancer centers are much more likely than those treated in the community to learn about the option of participating in a clinical trial.
- The 97 percent of adult cancer patients who are not involved in clinical trials may not receive the best available standard of care. Many communities lack resources to ensure that the unique needs of older cancer patients and survivors are met.
- The Internet has become a primary resource for cancer information, but older adult survivors are less likely than younger ones to have access to the Internet. Furthermore, the Internet is a source of misinformation as well as accurate information; a clearinghouse is needed to identify the most reliable online cancer resources.
- Neither oncologists nor primary care physicians are adequately informed about the long-term effects of cancer treatment and the follow-up needs of older survivors. Insurance companies often do not cover the types of testing older cancer survivors need.
- The point of diagnosis is not the "teachable moment" at which to address prevention and health behavior issues. Some long-term issues, such as fertility, need to be addressed immediately, but others can wait. The teachable moment occurs at the point at which a cancer patient begins the road to recovery.
- Lack of Medicare coverage for preventive care is a barrier for elderly survivors. Many doctors use disease-related Medicare codes when older survivors visit for preventive care so that the visits will be covered.



- The ability to perform breast cancer risk assessments has advanced to the point at which it may soon be considered a standard of care. As risk assessment testing becomes available for various cancers, these tests should be covered by Medicare.
- Effective insurance reform will not occur unless a grassroots movement makes it clear to lawmakers that this is a major priority. Advocates can use recommendations from the Panel's 2000–2001 report, *Voices of a Broken System: Real People, Real Problems*, to communicate with legislators and policy makers about needed changes.
- In spite of recent Medicare reforms, cancer patients remain at risk of being provided with the least expensive rather than the most effective drugs.
- There are two types of health care in the United States: state-of-the-art care provided in high-profile academic centers and large urban medical centers and that provided in rural areas, which is not always of equal quality. The same high quality of care should be available throughout the country.

## **TESTIMONY FROM PROVIDERS/INSURERS—GROUP II**

### **Presenters**

**Dr. Richard Migliori**

**Dr. Basil Kasimis**

**Dr. Sharad Mansukani**

**Dr. Michael H Kanter**

### **DR. RICHARD MIGLIORI**

#### **Background**

United Resource Networks focuses on credentialing and contracting with transplant centers and physicians by selecting medical centers and programs representing the best standards of care to increase patient survival rates while lowering costs. Prior to becoming CEO, Dr. Migliori was Chief Clinical Strategist for Ingenix, the health intelligence business unit of UnitedHealth Group. He currently serves on the Harvard University/Kennedy School of Government Health Care Delivery Policy Committee and is a member of the Board of Directors for Spectera, a vision benefits provider. Dr. Migliori served as Clinical Instructor and Associate Director of the Surgical Residency Training Program in the Department of Surgery at the University of Minnesota from 1989 to 1993. He led the development of national breast cancer detection guidelines and has published widely on a range of topics. Dr. Migliori, a member of the American Society of Transplant Surgeons, received his medical degree from Brown University, obtained advanced training in solid organ transplantation at the University of Minnesota, and completed a National Health Research Fellowship in immunology, transplantation, and oncology at the NCI in 1986.

#### **Key Points**

- The UnitedHealth Group provides for the AARP a Medicare supplement and other forms of individualized insurance solutions. These programs serve 3.7 million AARP members. UnitedHealth Group also serves 17 million Americans in employer-sponsored health insurance programs. About five million of the Group's customers are older adults.
- Persons with cancer are not excluded from insurance plans purchased from UnitedHealth Group by employers. When policies are offered to individuals, some restrictions exist related to cancer, but they are not overwhelming.

- A person who becomes eligible for a Medicare supplement has six months to enter the program with no questions asked. For those who wait longer, past and current health care history become relevant, and benefit design may be narrowed.
- When UnitedHealth Group covers patients with cancer, it tracks those patients to make sure they are doing everything necessary to help prevent recurrence.
- The trend toward increased cost sharing for covered individuals in the American insurance industry is a result of increasing costs of care and the increasing number of services being offered. In terms of cost sharing, cancer patients are not treated differently.
- UnitedHealth Group offers, as a separate product, access to alternative care strategies.
- UnitedHealth Group encourages participation in clinical trials and offers “compassionate use” exceptions so that patients can receive experimental treatments where indicated.
- In the past year, 3.6 percent of UnitedHealth Group’s employer-covered individuals and 11.5 percent of the company’s Medicare supplement customers sought treatment for cancer.
- While cancer prevalence among the company’s customers has grown by only 0.5 percent over the past year, annualized costs per patient have grown by about 14.5 percent. Rising costs are fueled by expensive new treatments, administrative expenses, futile care, billing errors, and misaligned incentives.
- Market-to-market variation in physician service rates per patient underscore the dissociation of practice from science. Variations in clinical practice are associated with idiosyncratic practice patterns, inconsistent application of evidence-based medicine, and incomplete patient information. These variations in practice result in outcome disparities.
- The fragmentation of our complex medical delivery environment disrupts the continuity of care. This is exacerbated by inefficient patient data collection, storage, analysis, and retrieval.
- Disenfranchised patients in our health care system sense a lack of control and self-determination.
- The American health care system, on the positive side, consists of highly talented physicians and institutions with exceptional clinical capabilities and technologies. To improve this system, UnitedHealth Group has four recommendations:
  - Establish evidence-based medicine as the standard of care.
  - Utilize the mass of available data on behalf of the patient in need.
  - Empower the patient as a consumer and allow market forces to drive rational pricing and efficient distribution of all components of care delivery.
  - Install patient advocate systems to support patient decisions and facilitate conduct of care.
- Defining standards of care is the role of academic medicine, not insurance companies. However, the insurance industry can play a role in disseminating information about evidence-based medicine to practitioners, providing practitioners with feedback on how well their practices mirror standards of care, encouraging patients to comply, and supporting data collection and analysis.
- Decision support tools help doctors use collected data to monitor and improve patient care. UnitedHealth Group provides practitioners with an online report that contains an automated statistical

summary of their individual compliance rates with cancer screening and other evidence-based health maintenance behaviors.

- UnitedHealth Group's United Resource Networks program for catastrophic diseases uses Centers of Excellence to:
  - Measure clinical results and identify best performers.
  - Negotiate affordable prices at the best-performing institutions in return for promoting those Centers.
  - Empower patients using this collected clinical performance and cost information to choose Centers worthy of the privilege and responsibility for their care.
- Skilled clinical professionals can offer the continuity characteristically threatened by our highly fragmented health care system. Holistic care is required to support patients in dealing with associated psychological, social, and physical effects of cancer and its treatment.
- Implementing these recommendations could reduce variations in care, produce improved short- and long-term outcomes, lower medical costs, and redistribute resources to better serve the growing numbers of cancer patients and survivors.

## **DR. BASIL KASIMIS**

### **Background**

In addition to his work at the Department of Veterans Affairs New Jersey Health Care System, Dr. Kasimis is Associate Professor of Medical Oncology/Hematology at the University of Medicine and Dentistry of New Jersey (UMDNJ) in Newark and Adjunct Professor of Clinical Pharmacy and Pharmacology at the Rutgers University College of Pharmacy in Piscataway. He earned his M.D. and D.Sc. degrees at the National University of Athens (Greece) Medical School. His research interests include hormonal treatment for prostate cancer, chemotherapy for solid tumors, and pilot studies of new drugs. Dr. Kasimis has served as Principal Investigator on more than 60 research grants and authored or coauthored more than 120 peer-reviewed articles, book chapters, and scientific presentations. In 1996, he received the Gallo Award for Excellence in Cancer Research from The Cancer Institute of New Jersey and the State Commission on Cancer Research.

### **Key Points**

- The modern era of Veterans Affairs (VA) began in 1995 with a reengineering of the entire system by Dr. Kenneth Kaiser, then VA Undersecretary for Health. The dramatic improvement in delivery of health care to veterans resulting from this effort are summarized in an article entitled "The Effect of the Transformation of the Veterans Affairs Health Care System on the Quality of Care," published in the *New England Journal of Medicine* in 2003.
- The VA system's ability to improve outcomes for veterans has been enhanced by a Memorandum of Understanding, signed by the VA and NCI in the late 1990s, that allows the VA to participate in NCI-supported clinical trials. In New Jersey, 55 to 60 percent of the VA's newly diagnosed cancer patients are enrolled in trials.
- Areas in which the VA system still needs improvement include screening and follow-up. Screening is beginning to be addressed comprehensively; in Division III, almost 90 percent of veterans are screened for cancer. Follow-up is more difficult to improve because comprehensive guidelines for

following survivors are not available. Guidelines have been developed by several organizations for specific cancers, but no data are available to indicate whether or how accurately they are applied. Uniform application of available recommendations for follow-up for the entire population of cancer survivors would have a tremendous impact on outcomes.

- Screening and follow-up should be the responsibility of primary care providers, such as family physicians and advanced practice nurses. This will require improvements in the education of primary care providers to cover the continuum of cancer care.
- Cancer survivors have a unique ability to gain the attention of politicians and encourage them to advocate increased support for public education about cancer. Survivors are also better positioned than doctors to help newly diagnosed cancer patients understand the value and importance of participation in clinical trials.

## **DR. SHARAD MANSUKANI**

### **Background**

Prior to joining the CMS Office of Clinical Standards and Quality, Dr. Mansukani served as Senior Vice President and Chief Medical Officer of Health Partners, the largest independent Medicaid plan in the Philadelphia area. He has chaired a Department of Public Welfare interdisciplinary committee designed to develop statewide HIV clinical practice guidelines and serves on the Mid-Atlantic Regional Asthma Initiative, led by Dr. David Satcher, former U.S. Surgeon General. Recently, Dr. Mansukani was asked by the Governor of California to work with Medi-Cal, the state's Medicaid agency, to help improve its disease management programs. Dr. Mansukani received his medical degree from the Medical College of Pennsylvania and completed a residency in ophthalmology at the Scheie Eye Institute of the Hospital of the University of Pennsylvania, a fellowship in glaucoma at Wills Eye Hospital, and a fellowship at the University of Pennsylvania's Wharton School of Business. He is a faculty member at the Hospital of the University of Pennsylvania and maintains an ophthalmology practice.

### **Key Points**

- The Centers for Medicare and Medicaid Services (CMS) follows a formal, explicit decision-making process dictated by Federal law. Coverage and payment decisions for cancer treatments on both the regional and national levels are based on a series of criteria and evaluations. Services or drugs must first be FDA-approved for at least one use before Medicare can provide coverage for them. Most requests for coverage come from beneficiaries, advocacy groups, medical directors, professional societies, and manufacturers. Receipt of a request prompts an evaluation of the requested drug or service. CMS considers scientific evidence to determine whether health care outcomes are improved beyond the benefits of currently available drugs and services. Recent streamlining efforts have reduced the length of the coverage approval process to approximately nine months.
- The Medicare Coverage Advisory Committee (MCAC) is an external committee of 100 leading experts in various fields, including six consumer representatives and six industry representatives. This Committee evaluates study methodologies, study outcomes, generalizability to the Medicare population, risk-benefit ratios, and benefit-harm ratios.
- AHRQ—a technology assessment group that is separate from CMS and the FDA—is charged with independently evaluating new health care technologies. CMS uses information from AHRQ in coverage decision analysis.

- The majority (90 percent) of coverage decisions are regional. Allowing regional coverage decisions permits faster diffusion of new drugs and technologies into the community and provides flexibility in responding to community needs.
- National coverage decisions are prompted by both external and internal requests. External requests are often prompted when there is substantial variation among regional coverage decisions or when prior national decisions not to cover a service or drug are appealed. Internal requests often arise when extensive new literature about a drug or technology becomes available or when concerns about inappropriate utilization of a drug are raised. Examples of national coverage decisions made over the last few years include deep-brain stimulation for Parkinsonian disease, and PET scans for thyroid cancer, soft-tissue cancer, and myocardial perfusion.
- The law regarding benefits and coverage states that “CMS must not pay for a service unless it is reasonable and necessary.” The application of this “reasonable and necessary” standard includes examining the value of a drug, technology, or service and determining whether adequate clinical evidence exists to support the conclusion that the service will improve health care outcomes. Clinical trials are essential to understanding the value of drugs and services.
- Two Web sites can provide additional information: [www.cms.gov](http://www.cms.gov) is the main CMS site; [www.cms.gov/medcov](http://www.cms.gov/medcov) contains information about the coverage analysis group that makes coverage decisions, status of national coverage decisions, and procedures for initiating or appealing coverage decisions.
- The key to success with Medicare is to encourage manufacturers to meet with the FDA and CMS before trial designs, during phase study, and before endpoints are met to hear what CMS is looking for in studies.

## **DR. MICHAEL H. KANTER**

### **Background**

The Southern California Permanente Medical Group is the exclusive provider of medical care to more than three million members. Dr. Kanter oversees quality programs, compliance with state and Federal regulations, and clinical care of patients, including drug utilization review, member appeals processes, population care management programs, and research activities. He is also a cancer survivor. Dr. Kanter received his medical degree from the University of California, San Francisco and served his residency at the Harbor-UCLA Medical Center. He is author or coauthor of more than 30 journal articles and book chapters. He is a member of the American Association of Blood Banks, International Academy of Pathology, editorial board of the journal *Transfusion*, and Medical Advisory Committee of the Los Angeles American Red Cross. Dr. Kanter received the Kaiser Permanente Physician Exceptional Contribution Award in 2003.

### **Key Points**

- Kaiser Permanente is a nonprofit HMO operating in nine states; most members are in California. The medical group, which is independent of the health plan, includes teams of health care providers—nurses, physical therapists, pharmacists, social workers, and doctors—who work together to treat patients. In Southern California, the medical group is comprised of 3,500 doctors, 47,000 other employees, and 3.1 million members. Kaiser, the largest non-academically affiliated research program in the country, has about 25 cancer-related clinical trials in progress. Kaiser also conducts its own evidence-based reviews of new drugs, services, and technologies; 27 currently used evidence-based

guidelines are based on these reviews and other research. There are also 45 “consensus-based” guidelines, which are based on expert opinion and experience in areas where evidence-based research is lacking.

- Guidelines and treatment information must be immediately accessible at the point of service delivery. Kaiser has implemented mammography reminders, for example, that are printed into each patient’s record. Kaiser has also begun development and implementation of an electronic health record. Clinical practice guidelines can be embedded into electronic medical records, creating prompts for screening, treatment, and follow-ups based on the guidelines.
- At age 17, Dr. Kanter was treated for testicular carcinoma and participated in an experimental research program. He has published about 25 articles in peer-reviewed journals, mostly in the area of transfusion medicine. It would be very helpful for the Panel to talk to people who are both cancer survivors and cancer researchers.
- The medical research community needs to express its gratitude to clinical trial participants, who do the hard work in clinical studies and often get very little out of them; the main beneficiaries of clinical research are not the patients who participate in trials but the patients who receive new interventions after the trials are concluded. Thanking trial participants might in the long run help improve recruitment.
- One significant obstacle to participation in clinical trials is the large bureaucracy that has evolved around human subjects research. Most small health care systems find it difficult to adhere to strict requirements regarding enrollment. The Panel should support efforts to decrease the burden of regulatory challenges while still protecting patients so that small systems can participate in trials.
- Obtaining employment is critical to obtaining affordable insurance. More research on workplace discrimination against cancer survivors is needed.
- Kaiser has developed a patient disease management program through which patients are tracked to make sure they comply with recommended follow-up; case managers remind patients when necessary.

## **DISCUSSION—PROVIDER/INSURER GROUP II**

### **Key Points**

- CMS should work closely with the NIH and FDA to prepare for the expected increase in cancer incidence and prevalence, particularly among older Americans. Efficiency will be a major concern as health care costs associated with cancer escalate.
- The VA experiences a 12 to 15 percent increase per year in the number of cancer patients diagnosed and treated. VA costs are covered by two mechanisms: charges to private insurers for those who have insurance—in New Jersey, all of the major insurers cover the cost of clinical trials—and support received from Congress through the Federal budget.
- United Resource Networks uses four strategies to handle the increase in cancer incidence: improving earlier detection; using a “Centers of Excellence” model to help patients make better provider choices; providing broader application of and easier access to evidence-based medicine; and expanding the affordability of health care through efficient business practices.

- The American public should be informed that health care costs will rise with increases in screening. The cost of care has been increasing at roughly ten percent per year; Medicare reimbursement rates have risen about three percent per year.
- The Southern California Kaiser Permanente Medical Group is attempting to make more efficient use of nonphysician health care providers (nurse practitioners, pharmacists, etc.). This is a cost-effective way to provide better, as well as less expensive, care. Practice regulations tend to be poorly defined, very complex, and variable from state to state. The Panel should make a recommendation to simplify regulations and allow more liberal use of nonphysician health care providers.
- Kaiser Permanente covers all screening costs, based on the belief that detecting and curing cancer early is less expensive than treating advanced cancer.
- Advocacy is needed on a national policy level to enable Medicare to more broadly cover clinical trial services and cancer screening.
- The VA has implemented national screening guidelines and anticipates 90 percent compliance for all VA medical centers.
- Although privacy should be protected, protection is sometimes overreaching and inhibits the ability to share information in the patient's best interest.
- Private insurers should cover clinical trial services so that the number of adults in clinical trials can rise above three percent. Also, patients need to be educated about clinical trials. The NCI should revive its message that "the best clinical practice in oncology is participation in clinical trials." Not all cancer patients need to be enrolled in clinical trials—because some diseases already have high cure rates—but the option to participate should always be offered to patients.
- Nonphysician practitioners, such as advanced practice nurses, often encounter obstacles to grant funding and research opportunities because they do not have advanced degrees. These obstacles should be removed so that these practitioners can enrich the knowledge of the medical community.
- Nurses have a body of knowledge in common with physicians and other colleagues, but they also have unique areas of expertise. There is an implied hierarchical model of delivery of health care; in reality, the health care system is moving toward parallel collegial relationships among practitioners.
- Recent literature suggests that older patients are not offered access to clinical trials; providers may have a preconceived idea that older patients are too frail to withstand the rigors of aggressive therapy. As a result, providers tend to base treatment decision making for the elderly on data from studies that include only middle-aged and young adult patients.
- Medication use, misuse, and adherence are issues for the older population. Many patients have five to seven doctors, with no one coordinating care or medication. There is very little follow-up or research about adherence to medication schedules.
- The older population needs to be told that it is diagnosed with nearly two-thirds of all new cancers. If the perception of personal vulnerability were enhanced, older adults might become more interested in screening and early detection. Popular media rarely portray older persons with cancer.
- Other problems in the elderly include symptom confusion and fatalism. Many older Americans who were born during the Depression received little health care when they were growing up and are reluctant to "bother" their doctors. By contrast, baby boomers were the first generation to receive routine vaccinations; they maintain frequent contact with the medical establishment. When baby

boomers enter retirement, the older health care consumer's concerns and demands will be very different from those of today's elderly.

- Increasing diversity will also affect how the medical establishment educates older adults.
- Specific language in recent health care legislation allows providers and insurers to show CMS actual drug and service costs when they do not correspond with CMS reimbursements.
- Every time insurance rates are raised, some people make the decision to become uninsured. In other cases, rates remain the same, but deductibles increase and service coverage is reduced, often causing consumers to omit coverage for catastrophic illnesses.
- Patient advocates should coordinate their efforts with health care providers and insurers.
- The current shortage of nurses will not be ameliorated unless intensive education programs are developed to attract more gifted people to the nursing profession. Nurses should be encouraged to attend meetings of the Oncology Nursing Society.
- Every American is entitled to state-of-the-art health care from the most talented health care professionals that America has to offer. This will require focusing on scientifically proven interventions, making better use of available information and improved data collection, and developing personalized plans to support patients throughout survivorship.
- The Office of Cancer Complementary and Alternative Medicine at NCI explores alternative services and treatments.

## **CLOSING REMARKS—DR. LEFFALL**

Before adjourning the meeting, Dr. Leffall asked all speakers to gather at the front of the room to be recognized for their participation. He reminded participants of the Town Hall Meeting at 7:00 p.m.



**TOWN HALL MEETING  
LIVING BEYOND CANCER: CHALLENGES FOR OLDER ADULT CANCER  
SURVIVORS  
JANUARY 5, 2004**

In addition to the scheduled testimony, the President's Cancer Panel held a Town Hall Meeting to solicit input from the public on the challenges of living after diagnosis and treatment of cancer. [NOTE: The Town Hall Meeting was not limited to the concerns of older adult cancer survivors; it was open to all cancer survivors, caregivers, and others affected by cancer.] Dr. LaSalle D. Leffall, Jr., Chair, and Dr. Margaret Kripke represented the Panel. Dr. Andrew C. von Eschenbach, NCI Director, and Dr. Maureen Wilson, the Panel's Executive Secretary and an Assistant Director of the NCI, were also in attendance.

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

- Dr. Leffall introduced members of the President's Cancer Panel and explained the purpose of the series of Panel meetings on survivorship and the goals of the Town Hall Meeting. He then introduced the first speaker for the evening, Mr. Robert Zimmerman, Director of the Mid-Atlantic Region of the Department of Health and Human Services.

**WELCOMING REMARKS—MR. ROBERT ZIMMERMAN**

**Background**

Mr. Zimmerman is the Director for DHHS's Mid-Atlantic Region (Region III: Delaware, Maryland, Pennsylvania, Virginia, West Virginia, and the District of Columbia). He works with regional representatives to promote DHHS policies and initiatives, provides administrative oversight, and facilitates coordination of DHHS program field operations within the Region III Office. Previously, Mr. Zimmerman served as Pennsylvania's Secretary of Health. In this position, he was instrumental in shepherding Pennsylvania's Tobacco Master Settlement plan. His department also initiated comprehensive statewide tobacco prevention and cessation and health and research programs. Other initiatives implemented during his term as Secretary included focusing on minority and rural health disparities, regulatory reform, advanced technology, e-commerce applications, improved customer relations, and public education campaigns. Mr. Zimmerman also served as Deputy Secretary for Medical Assistance Programs in the Pennsylvania Department of Public Welfare.

**Key Points**

- Having spent 30 years in the field of public health, Mr. Zimmerman is especially interested in the "delivery" part of the cancer research and care continuum. These meetings provide an ideal forum for sharing collective wisdom on putting knowledge into practice.
- Many cancer survivors speak of the importance of humor and positive attitudes in facing the challenges associated with cancer. They discover that their own inner resources and the support of caring professionals and loved ones are blessings, and they are sharing these blessings with others through this series of meetings.

## **MODERATOR—MS. LU ANN CAHN**

Dr. Leffall introduced the moderator for the meeting: Ms. Lu Ann Cahn, anchor and medical reporter for NBC 10 News, a Philadelphia television station. In addition, she is a cancer survivor. Ms. Cahn explained the procedures to be followed during the Town Hall Meeting and introduced the first speaker.

## **MS. JoANN STETZ**

- Ms. Stetz has worked in gynecological oncology, radiation therapy, and data management for cancer clinical trials. When she was diagnosed with stage III ovarian cancer, this background provided her with many advantages that others do not have. Ms. Stetz would like to see more cancer patients have advocates/navigators to help them through the care process, especially in the beginning, when many important decisions are made.

## **DR. DOLLY McPHERSON**

- Dr. McPherson was well taken care of by Wake Forest University Hospital when she went through her breast cancer treatment. An important resource is a good, interested doctor.

## **MS. FLORENCE JAFFE**

- Ms. Jaffe emphasized the positive impact of supportive friends, family, and physicians in her treatment for acute myelogenous leukemia. She and her husband became volunteers for the Leukemia and Lymphoma Society and joined a support group to help them through the process.

## **MS. HELENA GRADY**

- The sudden lack of support after treatment is completed can be disconcerting. It is important to take time off from work, if possible. Returning to “normal” life is challenging, particularly when one’s ability to function physically has changed. Psychiatric support, when necessary, is tremendously helpful. Talking to other survivors is also helpful because they are able to relate to the cancer experience.

## **MS. SANDRA NORMAN**

- Ms. Norman is a cancer survivor and a cancer researcher; she is President of the American Cancer Society’s Pennsylvania Division. She expressed gratitude to the National Cancer Institute and Congress for the amount of funding and resources devoted to survivorship research. Long-term follow-up survivorship research is difficult to conduct, but it is very important.
- We need to ensure that medically underserved people do not get lost in the system and that they have the resources necessary to find care, information, and services.

## **MS. DOROTHY SAUNDERS**

- Doctors do not always provide the information necessary to make an informed decision about treatment. In the surgery to remove a tumor from Ms. Saunders’ kidney, a rib was also removed; she would have liked to have been told that the removal of the rib might cause the pain and problems she now experiences. There is a stress attached to mystery, especially as it applies to the body. If the

patient knows there could be pain and discomfort as a result of treatment, he or she is better able to prepare for it psychologically.

- Ms. Saunders would like to see navigators helping patients through treatment and survivorship processes.

### **MS. APRIL DONAHUE**

- Ms. Donahue pointed out that the time after treatment ends is very stressful: each checkup brings fear that recurrence is happening. She feels that there is a need for more cancer treatments, specifically for ovarian cancer. Furthermore, it is necessary to look at the whole person in terms of quality of life. Mental health issues do not receive enough attention, and many people in treatment suffer from depression. Gaining support and connecting with survivors through different organizations can make a difference.
- Ms. Donahue encouraged all consumers to take control of their own health care, be advocates, and try to get involved. Every cancer center should have consumer advocates.

### **MS. DIANE PHILLIPS**

- Colon cancer is one of the few cancers that can be prevented through screening, yet there are still many barriers to screening. Insurance companies do not want to cover screening, even in the face of research showing that screening is cost effective. Physicians need to be more positive about making recommendations for screening. The public does not know enough to demand screening after a certain age. Ms. Phillips asked the Panel to lend its voice in support of breaking down barriers to colon cancer screening.

### **DR. CHRISTOPHER HILLMAN**

- All of the women on the maternal side of Dr. Hillman's family die of carcinoma of the breast. Dr. Hillman believes his sister (an identical twin) is a survivor because of the nontraditional methods practiced in his family, including high antioxidant intake, stress management, and aggressive dietary control. Dr. Hillman would like to know whether future cancer research will address nontraditional methods to approaching cancer management.
- Dr. Hillman takes a moment with each of his patients to touch that person and say, "You are going to be okay." The impact of this in terms of communication with and well-being for the patient is tremendous. He feels that doctors must find a balance between clinical ability and compassion.

### **MR. BERNIE FITZGERALD**

- Mr. Fitzgerald, with his wife and eight friends, started the Breathing Room Foundation, which awards families dealing with cancer with various requested services, including meal preparation, housecleaning, and yard maintenance. The awardee suggests what service is most needed.
- Mr. Fitzgerald's wife was diagnosed with cancer 12 times over six years, finally succumbing in 1997. The Foundation grew out of a desire to honor and reward others who are facing cancer and maintaining a stable lifestyle, as well as a need to give to others what so many people gave the Fitzgeralds during their time with cancer.

## **MS. LORI CURTIS**

- Because attention is understandably focused on the person with cancer, the needs of the caregiver are often not addressed. It is difficult to find caregiver-centered support groups that are convenient, given the stressed schedule of a caregiver. Ms. Curtis suggests telephone support groups, Internet-based activities, one-to-one peer support matching caregivers with other caregivers, more opportunities for respite care, and more preparation from the health care team about what will be in the caregiver's future.

## **MR. MAL HOLLANDER**

- Mr. Hollander is a cancer practice administrator, a member of the Community Oncology Alliance, and an active member of the New Jersey Society of Oncology Managers. Mr. Hollander's practice has embraced integrative cancer care, including relaxation techniques during chemotherapy, Reiki, and massage therapy, all of which are centered on the treatment of the person and not just the cancer. Community oncology practices also need the ability to do more psychosocial work with patients and their families.
- This is a crucial time in cancer care. Many new drugs are in the pipeline that may change the treatment paradigm, but providers may not be able to deliver these drugs on a regular basis due to issues in the current health care system, including the new Medicare legislation. Mr. Hollander is not sure if his practice will survive through 2005. Providers need help and advocacy so that they can continue to help people survive.
- Cancer is a mixed blessing since it offers a chance to survive and live every day as a blessing.

## **MS. SILVIA LEE**

- Advocates and policy makers should pressure HMOs to help cancer patients with their care during and after treatment. Many of the medications that Ms. Lee was prescribed were covered only minimally, or not at all, by her HMO.

## **MS. ROSALYN McPHERSON**

- Ms. McPherson suspects that some doctors withhold information from patients who are members of racial or ethnic minorities because they assume that these patients will not be able to understand what they are told. As a result, many patients are not aware of the treatment options that are available to them.

## **MS. MAILEEN LOKICH**

- Ms. Lokich hopes that one day a definitive test for ovarian cancer will be developed so that women do not have to battle this disease with its cycles of remission and recurrence.

## **CLOSING REMARKS—DR. KRIPKE, DR. von ESCHENBACH, DR. ROWLAND, AND DR. LEFFALL**

Dr. Leffall thanked Ms. Cahn for her efforts as moderator, Ms. Lee for her participation as interpreter, and Mr. Zimmerman for his remarks. He then asked members of the Panel and NCI staff for their final remarks.

Dr. Kripke summarized several recurring themes the Panel has heard in stories from the older population of cancer survivors: people need education about transitioning out of treatment into posttreatment to alleviate fear and stress over recurrence and feelings of abandonment by the medical system; psychological needs, both during and after treatment, are not being met; survivors need information about alternative medicines and treatments; and there is a strong commitment on the part of cancer survivors to share their experiences and knowledge with other people touched by cancer. Many survivors in this population are living on fixed incomes, which come with their own problems. Fear of losing employment, insurance concerns, the importance of education, the importance of caregivers, and the importance of humor as a means of dealing with difficulties are other themes common to this population. Legislative issues are of more concern to this population than to groups represented at previous meetings. Cancer comorbidities such as diabetes and heart disease are unique concerns for older survivors. Dr. Kripke wondered how the necessary system adjustments and expansions will be paid for.

Dr. Rowland emphasized the great role survivors have played in the progress that has been made in survivorship issues since the inception of the NCI Office of Cancer Survivorship. Survivors' continued willingness to share their experiences and information is critical if progress is to continue. There is enormous human resilience manifest in people who face life-threatening illnesses. Survivorship begins the day of diagnosis and continues throughout a person's life, whether that life ends due to cancer or something else. Survivors also include family members and caregivers, who are on the front lines of the cancer battle. NCI is deeply committed to looking at the needs of family members and caregivers as well. Definitions of alternative medicine are changing; therapies once considered "alternative" are being mainstreamed. OCS has a study underway under Dr. Michael Antoni at the University of Miami that is protocolizing a cognitive behavioral stress management intervention. NCI is also studying the role of alternative therapies in the lives of those interviewed for the California Health Interview Survey.

Dr. von Eschenbach stated that we are now poised, from a biomedical research point of view, for success in the fight against cancer. The investment in cancer research has led to a point where cancer is beginning to be understood as a disease process. However, there is still a long road ahead, as cancer is not just a biomedical problem. Cancer is a societal problem, a cultural problem, a political problem, and an economic problem. Fighting it is going to require a comprehensive and integrated solution across the entire societal domain. The only way this will come about is through working together as a community. This is an area in which the greatest return on investment in cancer survivors will occur, because as the number of survivors increases, so will the number of active participants in the solution to cancer.

## **CERTIFICATION OF MEETING SUMMARY**

I certify that this summary of the President's Cancer Panel meeting, *Living Beyond Cancer: Meeting the Challenges of Older Adult Cancer Survivors*, held January 5, 2004, is accurate and complete.

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

Date: \_\_\_\_\_

LaSalle D. Leffall, Jr., M.D.  
Chair  
President's Cancer Panel