

MEETING SUMMARY PRESIDENT'S CANCER PANEL

IMPROVING CANCER CARE FOR ALL: REAL PEOPLE, REAL PROBLEMS— WHY DON'T ALL AMERICANS GET THE BEST AVAILABLE CANCER CARE?

May 24-25, 2001
Washington, DC

OVERVIEW

The President's Cancer Panel was chartered to monitor and evaluate the development and execution of the National Cancer Program (NCP) and to report to the President on barriers to Program implementation. This meeting was the last in a series of seven regional meetings exploring issues that affect the ability of communities to provide cancer care—including prevention, education/communication, detection/diagnosis, treatment, rehabilitation, and palliative and end-of-life care—to people in the diverse neighborhoods of the Nation. This meeting brought together representatives from six States and the District of Columbia to discuss these issues and the barriers faced at local levels and local- and State-level efforts to address them. The speakers included cancer survivors who described their personal experiences both with the disease and in obtaining needed information and treatment.

MEETING PARTICIPANTS

Department of Health and Human Services

Tommy G. Thompson, Secretary

President's Cancer Panel

Harold P. Freeman, M.D.

Frances M. Visco, J.D.

Dennis J. Slamon, M.D.

National Cancer Institute

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, President's Cancer Panel

Speakers

Sharon L. Anderson, R.N., B.S.N., M.S., Senior Vice President for Care Management, Christiana Care Health Services (Delaware)

Marsha Bienia, M.B.A., Director, Center for Cancer Surveillance and Control, Maryland Department of Health and Mental Hygiene (Maryland)

Brenda Billingsley, Community Representative (Delaware)

Jackie Bong-Wright, M.S.F.S., President and CEO, National Foundation for Vietnamese American Voters, Inc. (Virginia)

Eddy A. Bresnitz, M.D., M.S., State Epidemiologist/Assistant Commissioner, Division of Epidemiology, Environmental and Occupational Health, New Jersey Department of Health and Senior Services (New Jersey)

Deborah Watkins Bruner, Ph.D., Assistant Member, Population Science and Radiation Oncology, Director, Prostate Risk Assessment Program (PRAP), Fox Chase Cancer Center (Pennsylvania)

Vicki Burks, Community Representative (Pennsylvania)

Albert Calloway, Community Representative (Pennsylvania)
Edward E. Chisholm, Community Representative (West Virginia)
Karen Connelly, R.N., M.P.A., Director of Public Health Nursing, Virginia Department of Health (Virginia)
Judy Crow, Community Representative (West Virginia)
David Dalton, Community Representative (District of Columbia)
Nancy Davenport-Ennis, Founding Executive Director, Patient Advocate Foundation (Virginia)
Kathleen M. Dietsch, Director of Family Services, Hospice Caring, Inc (Maryland)
Robert L. DeWitty, M.D., Associate Professor of Surgery, Howard University College of Medicine (District of Columbia)
Jacquelyn E. Flowers, Community Representative (District of Columbia)
Charles E. Gabe, D.O., F.A., C.R.O., Medical Director, Princeton Radiation Oncology Center and Greenbrier Valley Cancer Center (West Virginia)
Bea Gaddy, B.A., M.S., Ph.D., Community Representative (Maryland)
Mawuna Gardesey, Minority Health Director, Delaware Division of Public Health (Delaware)
Susan Garrett, R.N., M.S.N., Clinical Coordinator, Greater Baden Medical Services, Inc. (Maryland)
Rani Haigler, M.S.W., L.G.S.W., Patient Navigator and Outreach Specialist, George Washington University Medical Center (District of Columbia)
Janet A. Harris, Community Representative (New Jersey)
Ann Marie Hill, M.B.A., Executive Director, New Jersey Commission on Cancer Research (New Jersey)
Elmer Huerta, M.D., Director and Founder, The Cancer Preventorium, Washington Cancer Institute, Washington Hospital Center (District of Columbia)
Phyllis Katz, J.D., Cofounder, Legal Information Network for Cancer (LINC) (Virginia)
Jarvis Kuo, Community Representative (Virginia)
Judith Lieberman, Community Representative (Delaware)
Elnora R. Marsh, Community Representative (Pennsylvania)
Kevin P. McCartney, Community Representative (New Jersey)
Mary Emma Middleton, N.P., M.S., A.C.N.P., O.C.N., Palliative Care Coordinator/Acute Care Nurse Practitioner, Greater Southeast Community Hospital (District of Columbia)
Susie Miller, Community Representative (Virginia)
Aide Montoya, Community Representative (Maryland)
Cinthia I. Prado, Latin American Community Center (Delaware)
Dean Prince, D.V.M., Community Representative (New Jersey)
Lora M. Rhodes, M.S.W., Coordinator, Advocacy and Survivorship Program, Kimmel Cancer Center, Thomas Jefferson University (Pennsylvania)
Michael Richardson, M.D., Chief, Bureau of Chronic Disease, Government of the District of Columbia Department of Health (District of Columbia)
Evelyn Robles-Rodriguez, R.N., M.S.N., N.P.C., Oncology Advance Practice Nurse, Cooper Health System (New Jersey)
Pamela S. Rutherford, Community Representative (West Virginia)
Alan Rutherford, Community Representative (West Virginia)
Joan Laurette Savary, Community Representative (Maryland)
Paul Silverman, Dr.P.H., Chief of Disease Prevention and Control, Delaware Division of Public Health (Delaware)
Tom Sims, M.A., Director of Health Promotion and Chronic Disease, West Virginia Bureau for Public Health (West Virginia)
Ellen L. Stovall, President and CEO, National Coalition for Cancer Survivorship (Maryland)
Gail Stevens, R.N., Health Center Nurse Manager, Delmarva Rural Ministries, Inc. (Delaware)
Bishop Imogene B. Stewart, Advocate, Inner City Communications (District of Columbia)
Joshua Sundquist, Community Representative (Virginia)
Linda Sundquist, Community Representative (Virginia)
Robert S. Zimmerman, Jr., Secretary of Health, Pennsylvania Department of Health (Pennsylvania)

MAY 24, 2001

OPENING REMARKS—DR. HAROLD P. FREEMAN, CHAIRMAN

In opening the meeting, Dr. Freeman noted that:

- This series of meetings grew out of the Panel's 1999 evaluation of the National Cancer Program, which identified a significant disconnect between research discoveries and the delivery of the benefits of this knowledge to the American people. The Panel concluded that the unequal burden of cancer on the poor, certain ethnic minorities, and the underserved must be relieved.
- The previous meetings in this series were held in Omaha, Nebraska; Burlington, Vermont; Billings, Montana; Nashville, Tennessee; Los Angeles, California; and Albuquerque, New Mexico. This meeting in Washington, DC, is the final meeting of the series. The process will culminate in a report to the President of the United States near the end of 2001.
- This meeting will include testimony from the District of Columbia and the States of Delaware, Maryland, New Jersey, Pennsylvania, Virginia, and West Virginia. In addition, an evening Town Meeting will provide an opportunity for the public to present questions and comments to the Panel.

DISTRICT OF COLUMBIA

Presenters

Dr. Michael Richardson

Dr. Robert L. DeWitty

Ms. Mary Emma Middleton

Bishop Imogene B. Stewart

Ms. Jacquelyn E. Flowers

Mr. David Dalton

DR. MICHAEL RICHARDSON

Background

According to the 2000 census, the population of the District of Columbia numbers approximately 572,000. The District continues to have about 25 percent higher cancer incidence and mortality among the African-American population than in any other racial/ethnic group. A comprehensive cancer control approach is being undertaken to achieve significant reductions in incidence, morbidity, and mortality from cancer through comprehensive and integrated approaches covering the continuum of care from prevention through palliation. Key questions are: Is the best cancer care being given? What prevents the best care from being given if it is not? What prevents the best cancer care from being received? The important issues include access, care given, and treatment given in general, and care given to minorities. These issues overlap and interconnect in many ways.

Through the newly formed D.C. Alliance, the District hopes to provide a network of care that will be more responsive to patients' needs and give them better access closer to where they live.

Key Points

- Because the District of Columbia has a potpourri of cultures, cultural considerations are important in the delivery of health care. For example, acceptance of Pap smears in the Asian and Muslim communities has been difficult to achieve, in terms of both performing the test and helping people

understand why it is important to do the test not just once, but repeatedly. Culturally appropriate ways of breaking down this barrier are being developed.

- The District's Hispanic population, currently 20 to 22 percent of the total population, is growing rapidly. This community is in some ways better served, from a cultural perspective, than some other groups, but greater accommodation of the differences among this heterogeneous population is needed. Issues addressed by Central Americans differ from those important to South Americans. In addition, gender issues related to how men and women interact in Hispanic cultures are important in planning and delivering care.
- In the African-American community, it has been difficult to overcome both beliefs that cancer is incurable (and, therefore, that regular screening is useless) and suspicions concerning clinical trials.
- Access to care has been expanded through the CDC breast and cervical cancer screening programs. There have been no instances of nontreatment due to inability to pay, because local hospitals have generally been very good about, at least, starting patients on treatment. However, some hospitals are more willing than others in this regard, and it is difficult to ensure that continuing treatment is provided as needed. In addition, hospitals in the District are not evenly distributed geographically; this situation presents transportation and access issues (including being close to one's support system), particularly for African-American patients.
- In order to understand and accept treatment, patients need someone who will spend the time necessary to explain and answer questions. The physician may not always be the best person to explain or to walk the patient through the emotional, personal, and medical minefield that must be traversed after a cancer diagnosis.
- Institutions (e.g., hospitals, departments of health, hospices) need to become more aware that the look of the facility, the way patients are treated, and the extent to which patients are accepted for what and who they are are all important determinants of whether the patient accesses care, returns to continue treatment, and tells friends and relatives that getting care is important. In addition, patients who want it need to be given more control over their care; the system must become more responsive to this need.
- In the District, one hospital takes most of the charity cases. Many patients do not want to go there because they do not want to be labeled charity cases, feel less empowered in this situation, and question the quality of care available at that facility.
- Though the District of Columbia is not large, transportation to care is an issue for some residents.

DR. ROBERT L. DeWITTY

Key Points

- Though we do not know with certainty the impact of cancer screening, we have to hope that through screening we are detecting cancers at earlier, more curable stages.
- Cost is a significant barrier to care. Fear of being diagnosed is another significant barrier to screening that must be addressed.
- Access to care is an issue, particularly when there also is a cost barrier. Washington's city hospital, which has provided much of the charity care in the area, is scheduled to close.
- The underserved in the District of Columbia are primarily the under- and uninsured. People with cultural barriers may be underserved as well. Lack of facilities and of awareness of available services contributes to underservice.

- Physician awareness of the need for cancer screening has improved and is not the problem it once was.
- Policy, legislative, and infrastructure changes are needed. Something must be done about the problem of lack of insurance. Patients without insurance tend to delay or avoid care.
- Patients screened under the CDC breast and cervical cancer screening program must receive a definitive diagnosis of cancer to have their treatment covered under Medicaid. Some physicians are performing biopsies in their offices free of charge to bridge this gap in the care system.
- Patients without coverage who do not qualify for Medicaid may find that some services (e.g., radiation or chemotherapy) are not available to them. Some patients choose mastectomy over lumpectomy and radiation for purely financial reasons.

MS. MARY EMMA MIDDLETON

Background

Ms. Middleton is a nurse practitioner with 12 years of experience in hospice and oncology nursing. She currently works at a hospital in the Southeast section of the District of Columbia; its patient population is virtually all African-American.

Key Points

- In the past 12 years, many changes, including the emergence of palliative care, have occurred in the health care system, but patient perceptions of health care management and cancer treatment have not changed significantly.
- Many patients are ignorant of the seven warning signs of cancer. Ms. Middleton recounted the cases of several patients who ignored symptoms or attributed them to other causes and did not seek care until they had advanced disease. In one such case, a patient who had had a hysterectomy never had a pelvic exam after the surgery; she was diagnosed with stage IV ovarian cancer.
- The effort and cost associated with getting to treatment is a significant barrier for many patients in the District. Those who must take public transportation are too fatigued and ill to manage multiple bus transfers and walking to reach treatment centers. In addition, although the Washington metropolitan area has a subway and bus system, many patients cannot utilize it because it does not come close enough to their homes. Some of these patients are too ill even to go up and down the stairs of their apartment buildings to get to a bus stop or subway station. In addition, the buses can be unpredictable; when the weather or traffic problems are bad, the barrier to care is a major one. Most of these patients cannot afford taxis and may not have anyone who can drive them to care.
- Financial issues are an important barrier. Ms. Middleton recounted the case of a patient who waited until he was Medicare-eligible before seeking care because he did not want to have to apply for Medicaid or be considered a charity case. His colon cancer had metastasized to his liver by the time he sought care. Another patient, though insured through her employer, delayed seeking care because she was the sole support of her 2-year-old daughter and did not feel she could take time off from work. She was found to have widely disseminated lung cancer.
- Some patients are so fearful of the word *cancer* that they cannot even speak it. Some have witnessed friends or relatives undergo surgery, chemotherapy, and radiation, only to succumb to the disease—often wasted and with ill-managed symptoms. Too often, even at the end of life, patients are not afforded the opportunity for palliative or hospice care. It is no wonder that patients hesitate to come in for cancer care.

- Health fairs, especially those in the community sponsored by local churches, seem to be an effective way of lessening fear of cancer screening and treatment. More screening is needed.

Recommendations

- Community, church-based health fairs should be promoted.
- Increased funding should be provided to the ACS to expand transportation services.
- The Medicare hospice benefit should be changed to allow patients to receive palliative radiation and chemotherapy. Currently, hospice providers have to conduct fundraisers to pay for patient care. The reimbursement rate for hospice care has not changed since it was established in the early 1980s.
- Greater focus is needed on education and educating the public, particularly minority and underserved groups. Public service announcements and information placed in targeted print media may be ways of accomplishing this objective.

BISHOP IMAGENE B. STEWART

Background

Bishop Stewart has operated a shelter for battered and homeless women in Washington, DC, for 28 years. In 1997, she was diagnosed with ovarian cancer. She subsequently learned that her sister, whom she had not contacted for some time, had died from ovarian cancer. Until that time, she had not considered the possibility that cancer might run in her family

Key Points

- Too often, physicians from the inner city leave the city rather than stay and provide care in their communities. There is a need to bring these doctors back to the inner city. In addition, there is a need for doctors to make home visits and shelter visits free of charge, as they did in the past.

MS. JACQUELYN E. FLOWERS

Background

Ms. Flowers was diagnosed with breast cancer in October 1999. She was the first patient at the George Washington Medical Center and Hospital to benefit from the Breast and Cervical Cancer Treatment Act. Ms. Flowers is a self-employed speaker and trainer who travels both domestically and internationally to conduct seminars and workshops. She is also a full-time caregiver for her mother, who is nearly 80 years old.

When Ms. Flowers first began getting mammograms 12 years ago, she was minimally insured and took advantage of the mobile mammography unit sponsored by a local hospital. She was told about the Women Into Staying Healthy (WISH) program in the District, through which she has been able to access breast and cervical cancer screening and cancer information. The program also provides transportation for those who need it.

One of the more difficult aspects of Ms. Flowers' personal cancer experience has been the feeling of being out of control of her life. She called upon her faith and the support of her family and friends to see her through.

Her biggest challenge, however, has been providing for the costs of her mother's medical care. Ms. Flowers' mother has a number of medical conditions for which the cost of prescription medications averages \$400 to \$500 per month—when her mother is not having any serious problems; her medication costs sometimes reach \$3,500 per month. Because of this expense, Ms. Flowers elected to forgo health insurance for herself.

When Ms. Flowers required cancer treatment, the Medical Center and Hospital performed her surgery at no cost. However, they were unwilling to provide her radiation therapy (\$33,000 to \$40,000) at no charge. It was this care that was supported under the provisions of the new Breast and Cervical Cancer Treatment Act. To date, she has not received any bills for her care.

In addition to trying to find affordable health insurance for herself, Ms. Flowers also is trying to secure long-term-care insurance for her mother.

Recommendations

- Ms. Flowers urged the funding of more mobile mammography units in the Washington metropolitan area, additional education and training for staff, support for doctors to enable them to provide free care (on occasion), and programs to help educate new health care providers and administrators that it is sometimes necessary to “go the extra mile” to help a patient.

MR. DAVID DALTON

Background

Mr. Dalton, age 55, served in Vietnam for 1 year in the mid-1960s. Ten years later, while working as a corrections officer in the District of Columbia, he became ill and was spitting up blood. He had insurance coverage through Blue Cross/Blue Shield and went to a number of hospitals, trying to get help. His symptoms were largely dismissed, with providers suggesting he was just another black Vietnam veteran with problems and probably smoked and drank too much (he did neither). Mr. Dalton decided to go to the Veterans Administration hospital for help. At first, he got the same responses, but he persevered and was eventually admitted to the hospital, where he was found to have a mass in his abdomen and abnormal blood counts. He was diagnosed as having Wiskott Aldrich disease. He underwent a splenectomy, and a biopsy was taken of the abdominal mass, which was found to be non-Hodgkin's lymphoma. However, the mass could not be removed because it was attached to his aorta. He was treated with chemotherapy and radiation.

Mr. Dalton tried to get assistance from the military because he believed his illness was related to exposure to Agent Orange, but he could get no acknowledgment from the military that there was a link between his disease and his exposure in Vietnam. He was unable to work at that time, but because he did not have tenure with the Department of Corrections, the disability payments he could receive were insufficient to support his family of seven. He secured assistance for the family through Social Security.

The mass in his abdomen shrank and then disappeared over the next 3½ years, and Mr. Dalton was declared cancer-free. However, he was told not to return to his corrections job, because if he were to be hit in the stomach or similarly injured, it could cause his condition to recur. Mr. Dalton felt he had no choice but to return to his job because he had a family to support. The job became increasingly stressful, however, due to budget cuts that resulted in more inmates at the prison but fewer staff.

Mr. Dalton began having sleep problems, involuntary facial movement, and nightmares in which his Vietnam experiences were mixed with his experiences at the prison. He was diagnosed with posttraumatic stress disorder (PTSD) and was put on psychotropic medication together with psychotherapy. After some

time, he was determined to be well enough to return to work, but his physician advised that he be transferred to a less stressful job situation. Because of the ongoing staffing problems, however, he returned to a situation that was more stressful than before. Due to a series of incidents, he was eventually terminated from his position.

Through the Veterans Administration, Mr. Dalton was able to return to college, receive his degree, and get a job with a major communications company. He had health insurance from one of the large HMOs in the area. Mr. Dalton developed persistent diarrhea and, despite attempts to self-treat with over-the-counter medications and several visits to the doctor, could get no relief from the condition. One evening, he had chest pain, and at the hospital, it was ascertained that he had other health problems. Testing determined that he had lung cancer. He was unable to get a referral to an oncologist through his HMO and went back to the VA for help. He was treated with chemotherapy. Since then, he has had a brain metastasis, which was treated with radiation.

Key Points

- Stress, from whatever source, can play a major role in cancer and the patient's response to treatment and outcome.

Recommendations

- People should be made more aware of the symptoms of cancer so they will know when to seek medical care.

DISCUSSION—DISTRICT OF COLUMBIA

Key Points

- Screening programs that offer transportation should make the public aware that these services are available. People may sometimes use lack of transportation as an excuse for not getting screened.
- For low-income people, especially those who lack personal means of travel, transportation costs are an element of cancer care costs. Public policy should be implemented to ensure that transportation costs are covered for this population.
- One barrier to access to quality health care may be the inclination of physicians to focus only on the presenting problem rather than take a holistic approach to the patient's health, which might uncover other problems that would otherwise go undetected. The current insurance system may exacerbate this situation, since, increasingly, patients must have a referral from a gatekeeper in order to be reimbursed for the cost of any test that might be done. Physicians no longer have the option of ordering or conducting tests they believe are necessary to diagnose a patient's condition.
- In the public health arena, there has been a shift in focus from infectious to chronic disease. However, Dr. Richardson noted that both in the District of Columbia and nationally, the percent of budget allocated to treatment of chronic disease has decreased. Instead, health departments are focusing chronic disease funds on prevention and screening, including nutrition and exercise. It has also been useful that there has been greater recognition that treatment funds must accompany screening programs so that people with detected abnormalities are not thrown out on their own to try to find treatment. Still, a disconnect remains in this area. One mechanism for addressing this disconnect is to expand eligibility for assistance programs so that people diagnosed with any cancer are eligible for coverage of treatment costs. In addition, HMOs must not be allowed to deny care through the gatekeeper system. Funding for health education of the entire family is needed as well.

- The District of Columbia Health Department attempts to conduct screening and chronic disease activities beyond those that are federally funded, but it is limited by its structure and financial deficiencies.
- Uninsured patients who have a positive biopsy often qualify for Medicaid, but the application process usually results in a sometimes lengthy delay in starting cancer treatment, which is very stressful for patients. In addition, some patients do not qualify for Medicaid but still cannot afford treatment. Eligibility guidelines need to be liberalized in cases such as these.
- Duplication of expensive medical equipment driven by a desire to be competitive in the marketplace is counterproductive to quality of care and the assurance that only appropriate health interventions are performed. The health care system needs restructuring to address this problem.
- Physicians are taught that there is a prescribed manner and sequence of testing to determine a patient's problem. When, for financial reasons, insurers deny coverage for necessary testing, physicians are forced to tell patients that if tests or procedures are done, they may have to pay for them. Many patients will refuse to have a test performed because the cost is so high; this problem is a barrier to effective care.
- The public needs to be the determinant of what care should be paid for. To help remove disparities in care between populations and income groups, all stakeholders need to come together to review both interventions that are evidence-based and those that are need-based.
- Most people want to be able to pay their own way, and for many there is a stigma associated with being a "charity case." This does not mean that people are unwilling to apply for medical assistance, however, and there is a segment of the population that will accept charity care because they believe it is their right. But in Ms. Middleton's experience, younger patients seem especially sensitive to accepting what they perceive to be a handout, and older patients resist being a burden to their families. Even patients who are insured face copayments and deductibles that many cannot afford—if a 20 percent copayment totals several thousand dollars, it has a significant impact on family finances.
- Ms. Flowers disagreed with Dr. Richardson's view that there is an aspect of African-American culture that deems it acceptable to accept charity. She indicated that she has always been financially responsible, but at the time of her diagnosis was one of nearly 40 million working adults lacking health insurance. It is distressing to know that if she were billed for her care, she could not afford it and might have to refuse treatment. She noted how difficult it was to swallow her pride and apply for Medicaid to try to get assistance with the costs of the treatment she needed.

STATE OF DELAWARE

Presenters

Dr. Paul Silverman

Mr. Mawuna Gardesey

Ms. Sharon L. Anderson

Ms. Gail Stevens

Ms. Cinthia I. Prado

Ms. Judith Lieberman

Ms. Brenda Billingsley

DR. PAUL SILVERMAN

Background

Although the cancer incidence rate in Delaware has decreased (as it has nationally), the current rate in Delaware is 10 percent higher than the Surveillance, Epidemiology, and End Results (SEER) program national average. This gap is widening. A similar trend exists for cancer mortality in the State, which is 14 percent higher than the national average (as estimated from SEER data).

Key Points

- While a single statistic seldom tells the whole story, the population of Delaware is exceedingly concerned with the fact that the State has the fourth highest cancer rate in the Nation. Overemphasis on such a number can be a distraction in certain respects, but it has helped keep cancer on the public agenda. The State's cancer ranking is one reason that a committee has been formed to determine how best to address cancer comprehensively.
- Dr. Silverman envisions a coordinated, integrated statewide network of cancer-related services. While many people in the State are working hard on cancer issues, the State remains far from this goal. The State health agency should be a cancer control leader.
- Categorical programs and funding in health departments prevent comprehensive action. It is difficult to explain to clients in the breast and cervical cancer screening program why it is not possible to screen them for colorectal cancer—even though that cancer kills more people annually than does breast cancer—or why no efforts are in place to encourage family physicians to increase colorectal cancer screening.
- The impact of pollution on cancer is a significant concern for some agencies, such as the Center for Environmental Health in the Centers for Disease Control and Prevention (CDC) and the Environmental Protection Agency (EPA), but it barely registers as a concern on CDC's National Comprehensive Cancer Control Program. This lack of coordination definitely hinders the State's ability to respond to the public's concerns. Cancer is a complex, multifaceted disease requiring an integrated response, not categorical programs and categorical thinking.
- Coordination of community resources is hard work that takes time and commitment. Barriers include the competitive nature of community-level cancer services and difficulties in assembling the skilled human resources needed to execute an effective communication plan and organize the community. This latter difficulty is exacerbated by complex State contracting and hiring processes that undermine the perception that health departments can play an important coordinating role.

- We have failed to communicate the comprehensive nature of cancer control. The public wants a single “fix,” and elected officials are impatient. There also is a danger that in the economic downturn being experienced in Delaware and many other States, cancer education and awareness may be considered frivolous.
- The large system issues affecting cancer control are a major challenge. These include problems with transportation, health care, minority health, comprehensive school health education, and occupational health.
- Given the advances in knowledge about cancer at the molecular and genetic levels, this is a critical time to ensure that the health care system works, that cancer services are coordinated, and that new perspectives on cancer are being communicated to the public. State and local health departments can be essential partners in this endeavor, but only if ways are found to remove categorical restraints and invest in the public health infrastructure.

MR. MAWUNA GARDESEY

Key Points

- Delaware has at least a two-tiered health system that is a significant factor in health disparities experienced by racial and ethnic populations in the State. Like most other States, Delaware has racial disparity in cancer mortality.
- Anecdotal evidence suggests that research breakthroughs may be finding their way into the top tier of health care, but little evidence of any kind exists that these advances are reaching those served by the lower tier(s) of the system.
- Early detection and aggressive treatment are key to beating most cancers. Delaware considers this so important that it seeks out people at risk. However, no resources are allocated for timely, aggressive treatment. In essence, it is a search-and-rescue mission with resources for the search, but not for the rescue. Arguably, without a credible “rescue” component, the “search” may do more harm than good. Some would argue that it is unethical.
- Many people in minority communities have never known anyone who survived cancer. To them, a cancer diagnosis is a death sentence. Many do not want to know if they have cancer because it will just make their lives miserable to know there is nothing they can do about it. It is difficult to convince people that cancer is beatable because that is contrary to their personal experience.
- Lack of treatment resources makes it exceedingly difficult to persuade already reluctant people to be screened for cancer. Every occasion on which a person dies while we are looking for care, or when care is found too late to make a difference, only makes it more difficult to convince families and friends of the benefits of screening.
- A well-defined system exists for providing cancer care from diagnosis through hospitalization, but no equivalent system exists for coordinating posthospitalization care. Patients and their families are left essentially on their own to coordinate care and to negotiate with insurance companies to pay for it. Doctors who are experts in their fields and have staff support struggle daily to convince insurance companies to cover medically necessary care.
- Mr. Gardesey related the case of a health professional with terminal cancer: Although he had knowledge of the system and the support and care of family, friends, and colleagues, he could not persuade his insurance company to pay for a home health aide to manage his catheters. If such a person had such a difficult time navigating the health care system, patients less knowledgeable, less

connected, and with less supportive family, social, and professional networks are likely to have even more problems getting the care they need.

MS. SHARON L. ANDERSON

Background

Christiana Care Health System is a nonprofit, community-based health system, with few employed physicians. It is a large teaching center with its own residency programs. The system has its own health plan and a Visiting Nurse Association. Annually, the center has about 48,000 discharges and is one of the largest cancer care sites. Christiana Care sees more cancer patients than do most hospitals on the entire East Coast.

Key Points

- A major barrier to the best cancer care is unsophisticated, random, nontargeted outreach efforts for prevention and screening. Historically, outreach efforts have not been data-driven, in part due to limited funding. Outreach efforts have been sporadic and poorly supported, with little or no impact, and changing from year to year depending on funding. In addition, current methods of evaluation are unsophisticated and do not measure directly the effectiveness of the outreach effort. It is important to remember that the number of people who attend an outreach event does not equate to behavior change.
- To improve this situation, Christiana Care used State Tumor Registry data to identify the location of late-stage cancer diagnoses and map them by ZIP codes. Next, the geographic location and reach of all outreach activities (including awareness, education, and screening activities by community-based providers, other hospitals, agencies, and others) were overlaid on these maps. These maps have been completed for all major cancer sites. The process has highlighted gaps in screening and prevention activities and shown where activities have missed high-risk populations.
- Meetings have been held with community agencies that conduct outreach and screening to reduce duplication of effort and improve targeting of activities.
- Christiana Care and the State Division of Public Health also utilize mobile mammography screening to improve access for targeted populations. The van has historically offered only mammography services, but with the help of the State, its services will expand to include cervical and other high-risk cancer screenings.
- A Parish Nursing Program has been developed to more effectively address the African-American community in Wilmington. The program enables creative programming to access high-risk populations. The effectiveness of these efforts will be measured by the reduction in late-stage disease.
- Cancer care is a cottage industry in this country, where the incentives are for individual entities (either physicians or hospitals) to treat isolated episodes of illness. A cottage industry is not capable of providing for all the elements necessary to address all aspects of cancer care in a coordinated and sophisticated way. The best cancer care requires an organized system of cancer care delivery for the entire spectrum of cancer care services.
- To meet this challenge, Christiana Care has introduced a Nurse Care Coordinator program that provides continual assessment of patients' needs and seamless access to services. A Nurse Care Coordinator is assigned to and follows each patient from the time of diagnosis throughout the continuum of care. All Nurse Care Coordinators are oncology-certified, and some are Master's-prepared in oncology nursing. Every nurse is assigned by cancer site so that each becomes expert in that site, knowing the disease and available resources. The nurse coordinates all aspects of care delivery, from diagnosis to treatment to management of the disease, complications, posthospitalization issues, and end-of-life care, regardless of setting. This relationship will probably

become a lifelong contact for the patient, whether he or she receives services in a doctor's office or at a radiation oncology site. Nurses make home visits and do inpatient discharge planning. The program thus provides continuity and coordination of care and decreases duplication of services.

- In addition, this model improves information management among providers of care. Information management is critical in cancer care, since treatment involves multiple providers in multiple settings. The nurses serve as resources for the patient and provider, gathering information for second opinions and relieving the burden of information coordination for both the physician and the patient. They also push the providers, the physicians, and the system to deliver the most effective and expedient cancer care possible.
- Further, by monitoring the care delivery process, Christiana is able to identify and educate providers who are not following best practices.
- Christiana's care teams include social workers, who also follow patients regardless of the setting. Health psychologists, nutritionists, therapists, pastoral care providers, parish nurses, and other providers are included as needed.
- Most of these activities are supported by endowments, since these services—provided to every patient regardless of financial status and treatment setting—are not reimbursable.

MS. GAIL STEVENS

Background

Ms. Stevens, a registered nurse, has worked for over 22 years for Delmarva Rural Ministries, a private nonprofit organization located in Dover, Delaware. Currently, she is its Health Center Nurse Manager.

The organization was formed almost 30 years ago and is committed to ensuring access to health and social services for those who face myriad obstacles, including financial, language, cultural, and transportation barriers. Populations served include farmworkers; the under- and uninsured, including those who may be uninsured but working; and some homeless individuals.

Health care services are provided through three main programs. The newest of these, in operation for 4 years, is the Kent Community Health Center. The Health Center began as a collaborative endeavor between a local hospital and the Division of Public Health in response to a community health needs assessment. The Health Center has treated more than 5,000 patients since its inception and now sees close to 20 patients a day, with an average of 3 new patients a day.

The MATCH (Mobile Access to Community Health) van has been in operation since 1994, traveling to rural areas in lower Delaware. It provides nurse-based screenings, such as blood pressure and blood glucose testing, and immunizations to children who do not have a medical home. The program now has two vans, the second being used for primary care outreach to the farmworker and other rural populations in Sussex County.

The Farmworker Health Program has been in operation since 1975, annually addressing the health needs of nearly 2,000 farmworkers who harvest Delaware's fruit and vegetable crops from April through November. Nurses and case managers visit the labor camps to provide direct services and to refer patients, as needed, to the Kent Community Health Center, which has become a medical home for many of these workers.

Key Points

- Cancer screening and detection programs need to be marketed to the most underserved populations in ways that will reach them personally, such as speaking at housing programs, shelters, senior centers, and churches, where individuals can be enrolled at the presentation for specific cancer screening programs.
- Services need to be provided at accessible locations and times. This may include evening hours, Saturdays, and even Sundays after church services. Mobile health vans can extend services into local neighborhoods and into the far reaches of rural communities where services are often precluded.
- Collaborating with other agencies, such as local hospitals or the Division of Public Health, and utilizing a Community Health Center to provide a screening or educational program have been effective. Delmarva Rural Ministries has collaborated with different hospitals on its programs and with the hospitals' own screening interventions.
- Coordination with those who fund diagnostic testing or specialist consultations is also essential. For instance, one program may provide a screening mammogram but not a diagnostic ultrasound. Another program may pay for specialist consultations, but not for biopsies for detection of breast cancer.
- Uninsured patients need emergency financial assistance to enable them to receive treatment and medications promptly.
- Pharmacy assistance programs need to be enhanced and expanded to provide pain management and chemotherapy medications.
- Medicaid policy needs to be assessed to ensure that patients applying for assistance can qualify promptly so as not to delay treatment. These patients could receive retroactive eligibility and should not be placed in situations in which they have to give up their incomes in order to qualify.
- Case management programs are needed to support patient needs from diagnosis through treatment. Patients overwhelmed by their diagnoses need assistance in seeking out already established programs, such as support groups, transportation, and home assistance. Patients should be assigned one case manager who can provide continuity. In addition, case management programs should be placed at the local level to help promote accessibility.
- Ms. Stevens cited the case of a farmworker from Florida who told a program outreach nurse that she had had a breast lump for approximately 6 months but had not yet sought medical care because she was afraid. Although she was still fearful, and hesitant to seek a medical provider, the nurse encouraged her to come in to the health center. Within a week, the patient had a mammogram, an ultrasound, and a consultation with a surgeon. She had an oncologist appointment scheduled within a week. Within a month of diagnosis, she had had a mastectomy and had begun chemotherapy. Prior to surgery, she was living in a labor camp and later moved into a shelter. With the support of several organizations, the patient was able to locate housing in the area so that she could continue care and cease the transience that would have made continuity of care an issue. Fortunately, her physicians continued care despite the patient's inability to pay, and she finally received Medicaid. The patient is now settled out of farm work and continues to live in the area. She can be counted as one of the more successful patients, accessing not only health care, but supportive social services as well. Importantly, intensive case management was necessary to help the patient at almost every juncture. Sadly, not all patients can receive the support required to assist them from diagnosis through treatment and, hopefully, to recovery.

MS. CINTHIA I. PRADO

Background

At age 10, Ms. Prado was diagnosed with Burkitt's lymphoma. In the course of her treatment, she had her right ovary removed, lost her hair, and was subjected to numerous lumbar punctures and spinal taps. Ms. Prado's condition was explained very briefly to her and her parents—who did not understand much English nor any of the medical jargon—as an experience that would be unpleasant but one from which they would learn, grow, and share with others. Ms. Prado is now 23 years old and an advocate for the Latin American Community Center.

Key Points

- Hispanic families coping with cancer must face and struggle with five major issues: (1) the language barrier; (2) lack of cultural sensitivity; (3) economic problems; (4) lack of communication within the family system itself; and (5) lack of resources.
- The language barrier is the most obvious one. Ms. Prado recalled the look of confusion on her parents' faces as they tried to understand what was happening to her. Many Spanish-speaking families today are in the same situation. Few of the medical staff in Delaware hospitals speak Spanish, and most institutions have not hired people specifically to interpret. Alternative methods have been used. These include a "1-800" translation number and AT&T Translator Services. In addition, Ms. Prado and other employees from the Latin American Community Center volunteer their services at many local hospitals. However, such arrangements are very impersonal, due to the inconsistency of interpretation by people who come and go. In addition, not all Spanish-speaking countries have the same definitions for words. One way to resolve this problem is for hospitals to hire a full-time interpreter so that services are consistent and professional.
- Lack of cultural sensitivity is a serious barrier for Hispanic families. Most have a strong belief in God and that everything happens because of God. This belief, along with other traditions, is important for providers to understand. Another well-known cultural characteristic of Hispanic families is *machismo*. The father is the one who makes all decisions. Such aspects of culture are important, and when they are understood, respect is given as well as received. Because there are so many different cultures within the Hispanic community, medical staff should have regular workshops and/or classes that focus on cultural differences.
- Multiple economic issues affect Hispanic families dealing with cancer. Many immigrant families are uninsured. To many, living expenses are more important than health insurance. Paying for transportation is another economic problem. Many families have to travel from rural to suburban areas for treatment, which means taking a bus and/or taxi, incurring additional expense. Possible solutions to these problems include providing more financial assistance, lowering medical insurance costs and copayments, building more medical clinics for the underserved population, and, perhaps, making residential living arrangements for the family when a patient must receive treatment far from home.
- Because the entire family is going through changes while coping with cancer, the family system as a unit changes. The main focus is on the child with cancer, but along the way, communication is lost within the family. For this reason, the family as a whole—not just the patient—should be treated. Ms. Prado noted that when she had cancer, information about her condition was kept secret from her. People, including her doctors, ceased talking *to* her, but they talked *about* her in front of her. She feels she lost her sense of self because her family and the medical staff treated her as an illness rather than a person. Her sisters never communicated to her parents how they felt in general, nor did her parents discuss their feelings. Neither Ms. Prado nor her family ever had a social worker. Such assistance, particularly from a person who spoke Spanish, would have been of great benefit to the family. There is a definite need for bilingual social workers in hospital settings. Family therapists who specialize in families and children coping with cancer are also needed.

- In addition to financial and emotional resources, Hispanic families often lack understandable educational and/or informational literature about cancer. Many hospitals in Delaware lack information in Spanish on certain types of cancer. Such information is needed. Further, support groups conducted in Spanish for parents and for children would be emotionally and mentally comforting.

MS. JUDITH LIEBERMAN

Background

Ms. Lieberman is a breast cancer survivor. She also lost her husband to a rare gastrointestinal stromal tumor (leiomyosarcoma).

About 6 months before her husband's diagnosis, Ms. Lieberman and her husband dropped their health insurance because they could no longer afford it; they had just purchased a small business and were waiting for it to prosper. Mr. Lieberman subsequently developed symptoms of what he thought was a hernia. He decided to seek medical care at a later time, when he could better afford it. However, he later began experiencing appendicitis-like symptoms. He went to the emergency room, where his white blood cell count was found to be elevated. Thinking he had a ruptured appendix, the hospital performed immediate surgery, which lasted nearly 6 hours. Afterward, the surgeon told Ms. Lieberman that he had never seen a case like her husband's: A tumor the size of a football had ruptured and had been removed. The hospital pathology lab judged the tumor nonmalignant, but a second laboratory, which specialized in gastrointestinal cancers, confirmed that the tumor was an exceedingly rare sarcoma that is unaffected by chemotherapy or radiation and usually recurs at the same site.

Mr. Lieberman's surgeon encouraged the family to apply for Social Security Disability Insurance (SSDI) and medical aid to protect the family. They were not surprised to be initially denied for SSDI; they did, however, qualify for Medicaid. The hospital also wrote off part of its bill.

Three months later, Mr. Lieberman again experienced symptoms similar to appendicitis. This time, the tumor was found to have attached itself to his bladder, a part of which had to be removed. After explaining how little was known about Mr. Lieberman's cancer, the family finally qualified for SSDI.

Through the Internet, the Liebermans learned of the sarcoma unit at Memorial Sloan-Kettering Cancer Center in New York City and made an appointment. At a consultation, evidence of recurrence was noted, and a presurgical visit was scheduled. However, during this visit, Ms. Lieberman was called to the financial office and told that she would need either insurance approval or \$20,000 before Sloan-Kettering would admit her husband. Frantic, and ready to sell their home, Ms. Lieberman contacted one of the supervisory caseworkers in Delaware who managed to get the needed approval. Over a period of months, the Liebermans traveled between Delaware and New York for Mr. Lieberman's treatments, leaving their four children in the care of family and friends.

When Mr. Lieberman again had surgery, more than 30 tumors were found, 6 of which were the size of softballs. Although it was not covered by Medicaid, he was enrolled in a clinical trial, but the treatment was unsuccessful. Mr. Lieberman underwent a fourth surgery, but it was of no use. He subsequently died from his disease, 14 months after his initial diagnosis. Ms. Lieberman noted, however, that between surgeries, her husband felt relatively good and was able to enjoy life. The family was able to share important time together and received the support of friends, community, and church.

Unbeknownst to her, Ms. Lieberman's own cancer journey had begun 3 months before her husband's death, when she had her annual checkup and mammogram. Her doctor called several days later to say that the results were normal. After Ms. Lieberman's husband died, her periods became very erratic, and her

doctor prescribed birth control pills to regulate her cycle. Ms. Lieberman mentioned a history of fibroids in her left breast, noting that she had been told she could never take oral contraceptives. Her doctor indicated that the medication being prescribed would be all right because it was a low dosage.

About 9 months later, in June 2000, Ms. Lieberman noticed a change in the fibroid; it was also time for her annual mammogram. Her doctor said her chart indicated that her last mammogram was in 1995, but she had had a test the previous year. Later that evening, she got a call on her answering machine indicating that she must be anxious to hear about her mammogram from the year before. Speaking to her doctor an hour later, she was referred to a surgeon. The mammogram from 1999 had shown a 1-centimeter density, suspicious of malignancy; this was Ms. Lieberman's first knowledge of this. A mammogram taken days after the call showed that the suspicious area had grown to 3.5 centimeters, and a biopsy confirmed malignancy.

At that point, Ms. Lieberman sought to renew her Medicaid eligibility. Since she was receiving Social Security benefits following her husband's death, she had not thought she would qualify. However, she did qualify, and her eligibility was made retroactive to her diagnosis. Ms. Lieberman underwent a simplified radical mastectomy of her left breast. Of 16 lymph nodes removed, 1 was positive for cancer. Six weeks after the initial surgery, she began a series of chemotherapy treatments. Six weeks after that, she had a second surgery for reconstruction.

Ms. Lieberman believes that in her case, someone had "dropped the ball" for a year, which allowed a small problem to grow into a life-threatening situation in spite of multiple contacts with her doctor. If she had had the earlier mammography results, her life would not have been so drastically altered, and her children would not have had to go through so much emotional turmoil after first seeing their father die of cancer and then finding that their mother also had the disease. Knowing that the situation was avoidable and that she is the sole surviving parent of her children has made the experience that much harder to endure.

Ms. Lieberman does not believe her treatment was affected by her status as a Medicaid patient. In fact, she feels that the hospital and the people who worked with her were exceptional and that she was not denied any type of treatment. The practice that handled her case has many Medicaid patients—perhaps too many, she suggested.

Ms. Lieberman indicated that she must undergo further procedures to complete her breast reconstruction and will soon have her first 6-month checkup.

Key Points

- Delaware ranks very low in statistics on quality medical care. Greater doctor accountability is needed in cancer diagnoses. A central reporting followup mechanism might also be of benefit. With the help of a Nurse Care Coordinator such as those described by Ms. Anderson, Ms. Lieberman believes she would not have had the same experience.

MS. BRENDA BILLINGSLEY

Background

Ms. Billingsley is a stage IV colorectal cancer survivor. Beginning in 1996, she experienced periods of constipation and diarrhea and a vague feeling of discomfort in her abdomen. She informed her primary care physician, whom she had been with 10 years, of these symptoms. She was diagnosed with irritable bowel syndrome and sent to her gynecologist. After several visits, the gynecologist put Ms. Billingsley on hormone replacement therapy (HRT), although she was only 45 years old. Thereafter, whenever she

experienced the same symptoms, which was frequently, she was sent back to the gynecologist, who assured her that the symptoms were common side effects of HRT and would go away; however, the symptoms did not go away.

Ms. Billingsley had several fecal occult blood tests (FOBTs), all of which were negative. She also had digital rectal exams (DRE). Finally, in the fall of 1998, her doctor suggested that she might want to have a sigmoidoscopy. The words *tumor* and *cancer* were never spoken. Considering the preparation for the test, Ms. Billingsley decided to defer it, since she had never missed a day of work for this vague discomfort. Finally, she scheduled the test for January 1999. During the sigmoidoscopy, a tumor larger than a golf ball was found in the sigmoid section of the colon. Ms. Billingsley was sent for a colonoscopy and several CAT scans, and, from eight biopsies, the tumor was determined to be benign. Twelve days later, she had surgery. The tumor was malignant, and Ms. Billingsley was ascertained to have stage IV cancer with metastases to her liver and lymph nodes.

She was not told about her condition until 6 days after surgery because the surgeon did not believe she could handle the news. However, Ms. Billingsley knew something was wrong by the demeanor of the nurses. She was not really surprised to be told she had cancer, but she was very surprised to be told she had stage IV cancer. Shortly thereafter, she began chemotherapy but experienced side effects that required hospitalizations and delayed her treatment schedule. Ms. Billingsley was re-diagnosed with a liver tumor in July 2000. In addition to liver surgery, she had emergency surgery for a near-fatal blood clot. She has recently completed her second course of chemotherapy.

Key Points

- Several barriers prevented Ms. Billingsley from obtaining an early and proper diagnosis. First, her family physician practiced unreliable screening methods, the results of which were unquestioned despite her continuing symptoms. Most unreliable among these was the FOBT, which has been said to have a 50 to 70 percent false negative rate.
- Secondly, Ms. Billingsley was not knowledgeable about her risk for the disease. While she knew a great deal about breast cancer from public and workplace education efforts, she had no equivalent knowledge about colorectal cancer, even though the risk of dying from colon cancer is much higher than that for breast cancer.
- A third barrier to receiving timely treatment was her own embarrassment and discomfort. Her family doctor should have dealt with this discomfort directly and facilitated her receiving the sigmoidoscopy when it was first suggested. In fact, she should have been referred for a colonoscopy.
- Fourth, Ms. Billingsley had changed employment and for 3 months was on transitional health insurance under the Consolidated Omnibus Budget Reconciliation Act (COBRA). At the time the sigmoidoscopy was suggested, this insurance was not yet activated. Though she could have pushed the system to get the test done, she did not do so because of her embarrassment and discomfort about the test and her feeling that there was nothing really wrong.
- A fifth barrier to Ms. Billingsley's early diagnosis may have been the lack of an accurate family history. She did not learn until after her diagnosis that her father's grandmother had died of pancreatic cancer, and his grandmother's cousin had had colorectal cancer. Ms. Billingsley's grandfather likely died of colon cancer, though the cause of death was listed as dysentery. Most people have an inaccurate family history concerning colorectal cancer. Family doctors should not depend on that family history to assess risk but should, instead, assess whether the patient's symptoms could indicate colon cancer.
- In addition, the health insurance company covering Ms. Billingsley at the time would not have paid for a colonoscopy even if her doctor had requested it because she was not in a high-risk group. As a

colon cancer survivor, Ms. Billingsley helped lobby the Delaware legislature and was successful in securing passage of a State law that now mandates that all health insurance companies operating in Delaware pay for colorectal cancer screening. Delaware is one of only four States to have such a law. Current patients' rights legislation proposed by Senator Edward Kennedy would have a similar provision at the Federal level, but support for the bill is not strong.

- There remains a lack of insistence on the part of family doctors for screening first-degree family members. Ms. Billingsley's family doctor said nothing about screening other family members, but her colorectal surgeon strongly urged it. Ms. Billingsley has three siblings; one brother and one sister had precancerous adenomas that were discovered only because she had pushed them for a year to get screened.
- Delaware has one of the highest cancer mortality rates in the country. Nationwide, 37 percent of colorectal cancer cases are diagnosed at stage I; it should be 100 percent. But in Delaware, only 31 percent are diagnosed at stage I—6 percent lower than the national average—and each percentage point represents 22 people (or 132 people who could have had their lives lengthened).
- As soon as she was diagnosed, Ms. Billingsley called a friend who was the former head of the American Cancer Society in Delaware. This friend directed her to the very best practitioners in the field. Ms. Billingsley wonders what would have happened had she been less knowledgeable or poorer. For example, her colorectal surgeon found the tumor in her liver through manual manipulation, a procedure performed by some colorectal surgeons, but by almost no general surgeons. Her surgeon also recommended a hysterectomy as part of her surgery, because colorectal cancer often metastasizes to the ovaries in women in Ms. Billingsley's age group. Most oncologists do not recommend this preventive surgery, and many women develop these metastases, requiring additional surgery. In addition, some patients with colorectal cancer are being operated on by general surgeons rather than colorectal surgeons, and many develop numerous adhesions. Ms. Billingsley was also fortunate to have a physician who was research-oriented and who directed her to appropriate clinical trials. She has had vigilant followup care, including CEA tumor marker tests and CAT scans. She credits this followup care with finding her recurrence at an early stage.
- Ms. Billingsley was told that she would get disability insurance equaling 60 percent of her income. In fact, she got only 40 percent because there was a cap that her employer had not increased over the years. She had to fight to get the additional monies, which was an intimidating process. However, Ms. Billingsley now faces a dilemma: She has completed treatment and would like to use her education and skills, but if she works even a day in excess of 6 months, she will lose her private disability insurance.

DISCUSSION—STATE OF DELAWARE

Key Points

- Delaware is unique in that it does not have any State-funded treatment facilities. Christiana Care and the other providers provide free care, but it is not subsidized by the State. Christiana Care provides \$40 million worth of free care annually. It operates clinics at its Wilmington site, seeing about 60,000 underserved and uninsured patients a year. No cancer patient, either at Christiana Care or at other hospitals in Delaware, is turned away. For any positive mammograms taken by the mobile screening unit, all necessary care, including radiation and surgery, is provided free of charge. However, Christiana Care's financial situation has changed as a result of the Balanced Budget Act. As are other hospitals, Christiana Care is struggling and has had an operating loss for the past 3 years. The Patient Navigator program described earlier is funded by endowments, but the mobile mammography (a \$300,000 loss a year) and other free care are not. The funds supporting these programs are shrinking due to the Balanced Budget Act and changing reimbursements. Hospitals conduct the bulk of

outreach and free services and pick up where Federal funding—Medicare and Medicaid—leave off to ensure that this care is still delivered.

- The health care and reimbursement systems are terribly broken. Health care reimbursement currently provides incentives for all the wrong behaviors. Preventive care is not truly reimbursable; outreach is not reimbursable. Procedures are reimbursable. The financial incentives do not encourage preventive care or screening. We need a system that fixes the basic overall funding of health care. The incentives are wrong, and all of our programs are reactions to this system.
- The Panel often hears from providers about plans and programs that sound wonderful, but testimony from community representatives demonstrates that these programs do not reach certain parts of the population. Given adequate funding and/or universal access to health care, some populations will still face cultural and language barriers that must be addressed. A first step is to be out in the community to establish a level of trust. This may be particularly true for immigrant populations with legal status issues who may avoid the health system to avoid being recognized.
- In Delaware, decisionmaking concerning resource allocations for public health services is fragmented, involving the Division of Public Health, the Health Care Commission, and the Department of Health and Social Services. The State has yet to provide matching funds needed to participate in the Breast and Cervical Cancer Treatment program; advocates are recommending that Tobacco Settlement funds be used for this purpose.
- The cases of Ms. Lieberman and Ms. Billingsley illustrate that the problems of financial access to care affect more than just the uninsured, the poor, and the uneducated. Ms. Billingsley noted that she is a Canadian American who lived about half her life in Canada; she is a proponent of a universal health care system, with which she and her family had positive experiences in Canada. She believes a universal health system is especially important for people in her age group who are changing jobs more frequently and will be subject to economic downturns (and later upturns) that will exacerbate current problems. In addition, older age groups are more likely to be diagnosed with cancer. She does not believe anything less than universal access to care will resolve the problems people now experience.
- Ms. Lieberman noted that with greater doctor accountability concerning diagnosis, she might not have had to endure mastectomy and chemotherapy. In her husband's case, there was little information on his disease; patients with rare cancers have to be aggressive in searching for information and may need help in doing so. Dr. Freeman cited the recent discovery of Gleevec, which appears to be effective against the type of tumor Mr. Lieberman developed. Whether patients will be financially able to access this drug is an unanswered question at this point. Ms. Lieberman noted that the trial in which her husband participated was not covered by Medicaid, so the family had to make a significant financial decision in trying to save his life.
- Currently in the United States, health problems are identified; advocates become involved; and if sufficient political will is generated in response to the public will, laws are passed to address those problems. The Breast and Cervical Treatment Cancer Act is one example of this process in action. However, such laws typically restrict how the funds can be used. Public health officials struggle to provide comprehensive programming under these circumstances and would like more flexibility in how funds are used to better serve their distinct populations. Although agencies such as the CDC try to help in this regard, they, too, are restricted by these categorical and legislative restrictions. One solution to the problem may be to continue to try to impress upon Congress that cancer is a disease that must be addressed comprehensively.
- Even with universal access to health care, there will still be limited resources, and very difficult decisions will have to be made because universal access to health care does not mean access to everything a patient thinks might help or that a doctor thinks might be useful if there is insufficient

medical evidence to support it. In this regard, we may have to lower expectations and find the appropriate way to allocate resources. Many States would not be prepared at this point to determine how to allocate a large but limited pot of money if it became available. It is also true that if everyone had a health card, there still would be populations who would not take advantage of the system.

STATE OF MARYLAND

Presenters

Ms. Marsha Bienia

Ms. Susan Garrett

Dr. Bea Gaddy

Ms. J. Laurette Savary

Ms. Aide Montoya

MS. MARSHA BIENIA

Background

Like the District of Columbia and Delaware, Maryland has had high cancer mortality rates for many years. In 1990, Maryland had the highest cancer mortality rate in the Nation. In 1998, Maryland was eighth highest for cancer mortality. Maryland's cancer incidence and mortality rates reflect national trends, with lung, prostate, colorectal, and breast being the most common cancers.

In 1988, NCI published a Request for Proposals (RFP) inviting States to apply for funding to examine their cancer problem and develop priorities and a plan to address identified issues. Maryland received funding under this RFP and developed its priorities based on data and on proven interventions. The three identified priorities were tobacco use, breast cancer, and cervical cancer. At about the same time, Congress passed the National Breast and Cervical Cancer Mortality Act, which, for the first time, provided funds to States for screening, education, and outreach. In addition, because Maryland was number one in cancer mortality, the Governor and State legislature decided that they wanted to put State money into cancer control and provided State funds to pay for breast and cervical cancer treatment for uninsured individuals.

Using those Federal and State dollars, Maryland gave funds to the local public health system and to each of its 24 local health departments. The health departments worked with local private medical providers to identify those who could conduct screening for low-income, uninsured women. Medical guidelines were developed to help ensure quality care for these women. The State also hired lay health outreach workers in each community to find women, tell them about breast and cervical cancer, and get them into screening. Maryland funded screening and treatment for these women and also supported case managers at the local health departments to help the diagnosed women get the followup care they needed. This approach has been a major factor in reducing Maryland's breast cancer mortality.

In 1996, the State cancer plan was updated, and while colorectal cancer was identified as a priority, no funds were available to implement colorectal cancer-related programming. In 2000, Maryland was one of many States participating in the multistate Tobacco Master Settlement. The Governor and legislature decided to use the funds from the Tobacco Settlement both for tobacco control and to make Maryland one of the leading anticancer States in the Nation. Funds from the Tobacco Settlement were set aside for cancer research, education, screening, and treatment, with the goal of trying to reduce cancer mortality and disparities in cancer mortality among ethnic and other minorities. The model used for breast and cervical cancer is now being used to implement colorectal cancer programs throughout the State.

Key Points

- The barriers to providing cancer care to the population of Maryland are the same ones mentioned by others at this meeting. Lack of health insurance coverage has been a significant barrier, but Maryland has been fortunate to have State funds to provide for treatment of people with detected abnormalities.
- Providers are very busy, and reimbursement rates are very low; these two factors combine such that providers do not have time to spend on prevention.
- The public is confused as to what it should do about cancer. Messages about recommended interventions, behaviors, and screening tests are not clear. Those who are medically underserved have competing life priorities, and in many cases, getting cancer screening is not a priority. These populations need help and encouragement to carry through with the screening behaviors that could save their lives.

Recommendations

- Four things would help improve cancer care in the Nation: (1) universal health care coverage; (2) clear, and clearly promoted, messages about proven interventions that can reduce cancer mortality; (3) continued public health funding for activities such as those used in Maryland, including employing lay health outreach workers, paying providers to conduct screening, paying providers to render treatment, and paying case managers to help follow up with people with abnormal screening tests to make sure they get necessary diagnostic testing and treatments; and (4) more comprehensive cancer programs at local community hospitals so that well-trained and expert providers in cancer care will be located where people live and work.

MS. SUSAN GARRETT

Background

Greater Baden Medical Services is a Community Health Center in Southern Maryland, providing primary health care in medically underserved areas of Prince George's and Charles Counties. The Center provides care for both children and adults.

Ms. Garrett wrote an editorial about a real patient, "Lucinda," who has most of the characteristics of the underserved people in the community served by Greater Baden Health Services: She is uninsured, low income, lives in a rural area, and is non-English-speaking. Unlike some of the Center's patient population, however, she is a legal resident of this country.

Key Points

- For various reasons, adults face far more barriers to obtaining health care than do children. Lack of health insurance remains the number one reason people do not get the care they need. Adults without insurance often do not seek screening or preventive services. Indeed, they usually do not seek care when they first have a health problem. Instead, they wait, hoping it will go away. This is not surprising, since it costs between \$50 and \$100 for a visit at most doctors' offices—more if diagnostic tests are required. In addition to this cost barrier, the first question a patient is asked when calling to schedule an appointment is: "What type of insurance do you have?" Many physicians will not accept patients without insurance.
- Lucinda's case illustrates this issue. She noticed neck and abdominal swelling for months before she came in to see the physician at the Center. She was referred to a subspecialist at a major teaching

hospital who examined her, said she would die without treatment, and told her to come back when she had \$100,000 to pay for the treatment.

- In addition to lack of health insurance, many of Greater Baden's patients work in jobs with no benefits. If they take time off to go to a doctor's appointment, they do not get paid and risk negative consequences at work for taking the time off. While Lucinda does not work, she depends on her husband to drive her to appointments. He works 12-hour days for a nursery and must take a full day of unpaid leave to drive her to chemotherapy appointments.
- Lack of legal status is an additional impediment to obtaining health care.
- Many of Greater Baden's patients have young children and no one to care for them when they go to the doctor.
- Transportation is another barrier for many of the area's patients. In the more rural parts of the community, public transportation is very limited. For example, at the Charles County site, there is a county-owned van service that makes two trips per day to the Health Center. To use this service, patients must arrive at the Health Center before 9:00 a.m. and stay until late afternoon. Some, however, cannot get to the van stop from their homes. In addition, the available public transportation does not cross county lines. Most patients in need of subspecialty care are referred to Baltimore or to Washington, DC, but they cannot get there via public transportation.
- People who do not speak English have additional difficulties at every step of the process, from making an appointment to understanding their medical bills. Those scheduling appointments for non-English-speaking patients have been told by both physicians' office staff and hospital staff that these patients would not be seen unless they brought a translator.
- The two leading barriers to uninsured persons receiving specialty care are the requirement to establish a diagnosis before assistance can be obtained and assistance programs that are based on specific diagnoses. For example, Greater Baden accepts patients for primary care regardless of ability to pay but does not provide specialty care or certain testing. In Maryland, the primary financial medical resource for low-income persons is Medical Assistance, but to qualify, an adult must have an income below the poverty level and have a diagnosed disability. Adults who have an income slightly above the poverty level can qualify for Medical Assistance after they have incurred a certain dollar amount in medical bills. Unfortunately, specialists and hospitals are often unwilling to treat patients until they have Medical Assistance, so patients are unable to incur enough bills to qualify for Medical Assistance.
- In addition to the income requirements, adults must have a documented diagnosis to obtain medical assistance. This causes a significant problem for adults with cancer, as cancer must be diagnosed with a biopsy in order to be considered documented for the purposes of Medical Assistance. For example, the Health Center treated a man with bowel symptoms and a palpable mass in the rectum. The center's physician felt certain the man had cancer, but a biopsy was needed to establish the diagnosis. The man had no money and could not find a surgeon or a hospital willing to perform the biopsy until he had a source of payment. Lacking any alternative, the Health Center paid for the biopsy, which showed cancer. The man then received Medical Assistance and treatment. Everyone involved in caring for this man received reimbursement except the Greater Baden Health Center.
- The Center has extremely limited emergency funds available for such cases and used most of the funds for the year on this one person. As the Health Center has grown, staff are seeing an increasing number of people who need specialty testing and care, but the Center has insufficient funds to provide this level of care for everyone who needs it.
- While every resource is explored to obtain the care patients need, the time involved in finding these resources can lead to treatment delays. There is no comprehensive program to assist persons in need

of specialty care or testing. Instead, assistance programs seem to be based on the political popularity of the specific disease, and most are based on established diagnoses.

- In the case of Lucinda, the physician indicated that the possible diagnoses were cancer, tuberculosis, and AIDS. Ms. Garrett recounted hoping Lucinda had tuberculosis or AIDS because those diagnoses could be established at the Center, and it would be possible to get care for her. Once the diagnosis of lymphoma was established for Lucinda, Ms. Garrett spent weeks calling programs offering assistance to people with cancer, but these were disease-specific, and none targeted lymphoma patients.
- The Center staff attempt to convince local specialists and hospitals to see patients in need on a low-cost basis or with a payment plan, but they have had limited success. With the changes in insurance payments, many hospitals and specialists are financially unable to provide the level of charity care they performed in the past. Specialists and hospitals are more likely to write off charges if the patient is referred to them by a physician who also refers paying patients. Unfortunately, the Center does not refer many insured patients to specialists since it sees few insured patients.
- Ms. Garrett expressed the wrenching frustrations of trying to provide care to the Center's population: watching a young woman dying of invasive cervical cancer that did not respond to treatment because she was not diagnosed until very late in the disease process because no health care was accessible to her; telling a woman who has been watching television coverage of the need for early detection of colon cancer that she has many symptoms of colon cancer and needs further testing, but no source of care has yet been found; caring for a young man with a large skin cancer on his nose who cannot get medical assistance until he has a biopsy (which might spread the cancer), when no provider will remove the cancer until he has a source of payment; being happy when a patient's HIV test comes back positive, because an HIV diagnosis will enable the patient to obtain needed care and medications.
- Disparities in access to cancer care can be reduced. Community Health Centers, supported by the Bureau of Primary Health Care, provide primary health care to underserved and vulnerable populations. They do a wonderful job of integrating prevention measures into acute care visits. The Greater Baden Health Center regularly exceeds the published national average for preventive care provided, and no one is turned away because of lack of insurance or other barriers.
- Another potential model for reducing disparities is the Breast and Cervical Cancer Program as administered by Maryland's Department of Health and Mental Hygiene. This program provides outreach, screening, diagnostic testing, and treatment for breast and cervical cancers. Patients can receive diagnostic testing based on clinical findings rather than have to obtain a biopsy before they can get help.
- Lucinda is a real person. She has five children under the age of 10. The youngest is 3—a little girl who will lose her mother before she starts school. There are many people like Lucinda suffering and dying of treatable disease in our country of vast resources.

DR. BEA GADDY

Background

Dr. Gaddy indicated that for most of her life, she knew nothing about cancer prevention or early detection methods. She never received any cancer education. She believes she had cancer for 15 years before it was diagnosed. When her cancer was discovered, she had 39 positive lymph nodes. Though uninsured, she received surgery and other treatment at a cancer center.

Dr. Gaddy works at a program of feeding centers and shelters in the Baltimore area; people accessing the program are asked about history of cancer in their families. For those at risk under age 40, the program locates a source of services. Those older than 40 are referred to the State Health Department.

Key Points

- Funding is needed for cancer education, prevention, and outreach. Outreach should include individuals knocking on doors to reach and educate people.
- A universal health care system is needed that includes prevention, education, and outreach. Transportation is also an issue for many minority residents.
- Education cannot prevent cancer, but it can help a person know what to look for and when to seek help.

MS. JOAN LAURETTE SAVARY

Background

Ms. Savary is a 5-year survivor of stage II colon cancer. One year prior to her diagnosis, she and her husband had adopted two children. Ms. Savary had surgery to remove the primary tumor and then had 5 weeks of radiation with 24-hour continuous infusion chemotherapy. This was followed by 6 months of weekly chemotherapy.

Ms. Savary's husband is a self-employed dental technician. Health insurance had always been an expensive proposition for them. Before they had children, the Savarys had a policy with a \$2,500 deductible per person in order to keep the premiums at an affordable level. Mr. Savary had previously had back surgery for a herniated disc, and they were also struggling with infertility. Therefore, it would have been difficult to change insurance, since complete medical histories and blood and urine tests would be required.

When the Savarys adopted their children, however, they began looking for family policies. They switched to a more affordable insurance policy in December 1995. The policy included a rider imposing a waiting period before any services related to Mr. Savary's back would be covered. Four months later, Ms. Savary was diagnosed with colon cancer. The insurance company was immediately suspicious that her cancer was a preexisting condition and requested 10 years of medical records from every doctor she had ever seen. Since colon cancer develops relatively slowly, her condition likely did exist prior to her securing the new policy, but she did not know the cancer was there.

While struggling with life-and-death decisions, Ms. Savary was also worried that she would leave her children without a mother, and her family with insurmountable debt. Her treatment and surgery would cost over \$50,000. Nonetheless, she had to go forward with treatment in spite of the threat of impending debt hanging over the family. Fortunately, Ms. Savary had generous and caring doctors who told her she must be treated no matter what the financial consequence. Her insurance company would not pay claims for her treatment costs.

However, in July 1996, the Health Insurance Portability and Accountability Act of 1996 (the Kennedy-Kassebaum bill) was passed, providing that small business owners could buy insurance without being screened for preexisting conditions—giving them the same right as large corporations and government employees to change insurance for any reason. Suddenly, Ms. Savary's insurance company began paying her bills.

To help others who need help and to give back to the community as thanks for her own survival, Ms. Savary helped found and currently serves on the board of the Colorectal Cancer Network. The Network helps sponsor support groups, provides a variety of support and educational services, and maintains a Web site with a wealth of information, online support lists, and a one-on-one support program. The Network is also working to improve screening rates, clinical trial participation, and insurance coverage for all.

Key Points

- Were it not for the passage of the Kennedy-Kassebaum bill, Ms. Savary would never have been able to change insurance policies again, making it impossible for her family to get adequate and affordable coverage.
- Even if a person's condition is known to be preexisting, should people have to choose between getting a radiation treatment and feeding their children? Should people have to fear losing their houses in order to save their lives?
- Amazing new discoveries in research have made cancer, if not curable, certainly more manageable, but cancer care has also become prohibitively expensive. If insurance does not cover these costs, these treatments will be out of reach for most Americans. This is neither fair, nor is it good medical practice. But mostly, it would be inhumane to have so many people with empty pockets standing outside our hospitals looking in and wishing they had a choice.

MS. AIDE MONTOYA

Background

In 1997, Ms. Montoya began to notice that her abdomen was intermittently bloated. She went to the doctor, who referred her for an emergency sonogram. She was diagnosed with non-Hodgkin's lymphoma. Ms. Montoya, who had a 9-year-old daughter and 2 years earlier had separated from her husband, was distraught that she might die and leave her daughter alone.

Ms. Montoya was referred for a liver biopsy and to an oncologist. When she went for the liver biopsy—an unpleasant procedure—she was upset; she was treated rudely by hospital staff, who told her that if she could not calm down, she would have to come back another day. She was denied any kind of sedative, but she endured the procedure. On meeting with the oncologist 2 weeks later, Ms. Montoya asked about her prognosis. She was told that at most, she would live 5 years. The oncologist did not offer her any treatment options. When she asked about chemotherapy or radiation treatment, she was told that there was no point in these treatments because the disease would just recur and, she was told, “then we'll have to let you go.” She also was discouraged from the possibility of a bone marrow transplant. She was, however, referred for a bone marrow biopsy.

Two months later, nothing had been done to treat her cancer. Ms. Montoya begged for treatment so that she could try to survive for her daughter. At close to 4 months after her diagnosis, it was decided to give her radiation treatment. She had to have a repeat CT scan because the radiologist indicated that the first one was by then too old. The repeat scan showed that her spleen was now quite enlarged. It was decided that she should have chemotherapy before the radiation to avoid removal of her spleen.

Three months after completing the radiation treatment, Ms. Montoya began her followup care. Each time she went to see her oncologist, he told her that her lymph nodes were again becoming enlarged—just as he had told her they would—which again caused her to become very distraught. However, her radiologist

told her that some people have large, but normal lymph nodes and that since they did not have a baseline scan on her, they could not know if hers were enlarged or not.

Throughout her treatment, Ms. Montoya had been covered under Medical Assistance, but she received a letter saying that her coverage would be terminated because she was no longer eligible. When she went to the Medical Assistance office, she explained that she had cancer and needed to maintain coverage. She was asked for extensive paperwork, which she provided. She received a letter saying that her coverage would be terminated because her income was too high. Ms. Montoya earns \$700 per month, of which \$440 is spent on rent. This leaves \$260 for all monthly expenses for her and her daughter. She was told that in order for Medical Assistance to pay her medical bills, she would have to pay a deductible of \$1,560. Ms. Montoya felt she had no choice but to give up. She also was treated rudely each time she visited the Social Services agency and was asked repeatedly about her legal status, even though a copy of her citizenship papers was on file.

At her most recent followup visit, she told the doctor and hospital to bill her. She has no way of paying the bills, but knew she needed to be checked for recurrence. Ms. Montoya implored the Panel to help people who lack insurance and cannot afford the cost of cancer care.

DISCUSSION—STATE OF MARYLAND

Key Points

- To help solve the problem of lack of insurance, more resources must be put into health care. It may be necessary to phase in health insurance coverage for more Americans, possibly by increasing the medical assistance rate in a stepwise fashion over time. However, this can be done only with the will and the leadership of the Federal Government as well as the States. The issue of unrealistically low reimbursement rates is similar in many respects. Many providers try to help where they can, but they tell community health providers that they are losing money; we need to be able to pay them for their services.
- Many of our funding priorities are based on who makes the most noise. One example is breast cancer. Women have lobbied, formed groups, and created political pressure, so there are now options for treatment for women without insurance who have breast cancer. However, colon cancer is not that “popular”; there are no lobbying groups that have the numbers or the loud voices that breast cancer advocates have marshaled. The new Colon Cancer Program will provide for treatment of this disease, but there were previously no treatment options for uninsured people. People on the front lines who work with people who lack resources know that the current system is a terrible way to determine funding priorities. It would at least be sane to determine funding priorities by deeming that *every* person gets a certain level of care. But to have, for example, a patient with breast cancer for whom everything is available and another with lymphoma for whom *no* care is available is wrong, and it is very difficult for providers to deal with. Changing the current system may require changing the entire political process. One way to begin to make changes is to let people know what is happening to people currently. Rather than lobbying for more treatment for a particular disease, we need more people lobbying for treatment for everyone.
- Ms. Savary clarified that her insurance company never actually made a determination not to cover the costs of her colorectal cancer treatment because they were delaying until they received records from all of her previous physicians. However, she did not have any typical symptoms of colorectal cancer, and in conjunction with her infertility treatment, had had a laparoscopy and other testing that did not give any indication of a problem. She had had pain during intercourse, but her doctors ascribed it to tension. A year later, when she was diagnosed, it was discovered that she had a tumor just above the rectum that had displaced the colon so that it was lying at the cervix. This may have been causing the

pain. So while this might have been considered a symptom, no doctor ever suspected it to be due to colorectal cancer because at the time, Ms. Savary was only 44 years old. Any complaints were dismissed as “female problems” and stress over her infertility. After passage of the Kennedy-Kassebaum bill, the insurance company paid for all her treatment, even retroactive to her diagnosis. Ms. Savary believes they would not have done so but for the wording in the statute.

- The Breast and Cervical Cancer Program in Maryland may be the only program that covers diagnostic tests. If a woman finds a lump in her breast, and she has low income, the program will help her get a biopsy. This program should be used as a model to resolve the issue of requiring a diagnosis before payment for treatment is allowed when there are no funds to pay for diagnostic testing. Funding is limited, but it is far less expensive to pay for biopsies to diagnose and treat early-stage disease than to wait as we are doing now—sometimes months or years—until a person can get a diagnosis, at which time the treatment becomes far more expensive.
- Ms. Montoya believes that the delays in her treatment and the way people related to her concerning her disease were motivated by bias because she is Hispanic. She noted that at about the same time she was diagnosed with non-Hodgkin’s lymphoma, a Major League baseball player was diagnosed with the disease. He was operated on and treated immediately. She does not like to think that her treatment was related to her being Hispanic or not famous—and, therefore, not considered to be important—but she believes this was the case, particularly when her treatment did not begin for 4 months, and she had been given 5 years, at most, to live. She noted that everyone with cancer wants to live, and no one should be treated differently because of differences in culture, race, or nationality.
- Ms. Savary noted the striking difference between her experience and that of Ms. Montoya. In Ms. Savary’s case, the doctors said that they would treat her even if she could not pay; they talked her into being treated and insisted that it was *their* job to get the insurance company to pay, not hers. Unlike Ms. Montoya, she was treated immediately, without question. Ms. Savary, who is white, with blonde hair and blue eyes, believes she fit the profile of acceptability because of her appearance, despite her lack of financial resources. She believes there is always racial and cultural profiling in medicine. Ms. Montoya concurred.
- Ms. Savary echoed Ms. Garrett’s recommendation that a minimum standard of care be established that is available to everyone regardless of insurance status or ability to pay. Implementing such a policy would not eradicate the problem, since it is not possible to legislate bias from people’s minds, but if a patient has a source of payment, he or she will be treated. Programs like the Breast Cancer Program in Maryland are important steps toward ensuring that people receive needed care. The first step is to provide sufficient preventive care to all people, not just those who can afford that care. Establishing treatment standards and monitoring care provided and patient outcomes are also necessary.
- Provider education is needed to teach providers interpersonal (not just technical) skills and encourage them to take symptoms (especially women’s symptoms, which tend to be dismissed, particularly—though not only—by male doctors) seriously. This is especially important in the current health care environment in which people do not have a family doctor who gets to know the patient and his or her history over a period of time.
- Ms. Visco noted that in the early 1990s, when the breast cancer advocacy community was walking the halls of Congress trying to get universal access to health care, some of the barriers in the way of achieving that goal were the organized medical community and insurance companies. Though more patient advocacy was suggested to help overcome some of these barriers, it was acknowledged that there is no single solution. Multiple solutions are needed to reduce barriers to care, but some barriers based on bias will never be totally overcome.

STATE OF NEW JERSEY

Presenters

Dr. Eddy A. Bresnitz

Ms. Ann Marie Hill

Ms. Evelyn Robles-Rodriguez

Dr. Dean R. Prince

Mr. Kevin P. McCartney

Ms. Janet A. Harris

DR. EDDY A. BRESNITZ

Background

Eighteen months ago, New Jersey citizens were surveyed about their biggest health concern; cancer was the number one disease on their list. Age-adjusted cancer incidence rates in New Jersey are the second highest in the country for men and third highest for women. More than 40,000 new cases are diagnosed annually. The cancer incidence rate continues to rise, as it has in the whole Northeast, though not as rapidly as in the past.

Cancer deaths in New Jersey number approximately 17,500 per year. Overall, the age-adjusted mortality rates are somewhat better than the incidence rates: 7th nationally for women, and about 22nd for men. These rates also are higher than the national averages.

According to the 2000 census, New Jersey's population totals 8.4 million people, making it the 10th most populous State in the Nation. The population is becoming more diverse, with more than a third classifying itself as nonwhite.

The high cancer burden in the State is borne disproportionately by different parts of the population, with incidence and mortality for major cancers higher among the African-American population than among the white and Hispanic populations. This problem has existed and has been known for several decades. The legislature has attempted to respond to this problem by providing additional resources and making changes in policy and organization. One such action was to create the New Jersey Commission on Cancer Research in the early 1980s to promote both basic science and epidemiologic research in the State. Currently, the Commission awards more than a million dollars annually in State-appropriated monies, as well as another million dollars derived from license-plate revenues and donations.

New Jersey has a population-based cancer registry that was established in 1979. It has received numerous awards over the years and in 2001 was designated a SEER registry by NCI. The Registry is crucial for promoting and facilitating research efforts and responding to community concerns.

New Jersey's breast and cervical cancer screening program was started with preventive block grant monies in 1993. In 1996, it received funds from the CDC to focus on breast and cervical cancer, and it was further restricted to a relatively narrow age group. The monies are awarded as health services grants to local communities, targeting ethnic and racial populations, the uninsured, and the underinsured.

As were most States, New Jersey was a participant in the Tobacco Master Settlement Agreement. Due to State leadership, all of this year's funds (nearly a quarter-billion dollars) will be used for health-related activities, though not all for cancer control. Almost \$3 million is being used to expand the Cancer Education and Early Detection (CEED) program—not only to those eligible for breast and cervical cancer screening, but also to provide screening services for prostate and colorectal cancers through health

services grants. Though still a categorical approach, the program addresses the four major cancers in the State.

The Master Settlement Agreement also provides \$30 million annually for comprehensive tobacco control—about 10 percent of New Jersey’s tobacco-related dollars. This amount is not as much as the CDC recommends, but it is sufficient to give New Jersey a fairly credible program.

Prior to stepping down as Governor to join the Federal Government, Christine Todd Whitman issued an Executive Order establishing a State Task Force on Cancer Prevention, Early Detection, and Treatment, which is charged to develop a statewide Comprehensive Cancer Control Plan; its report will be presented to the new Governor by July 2002. Once passed, funds will be needed for implementation. Former Governor Whitman also appropriated \$200,000 annually in the base budget to support this effort and to establish an Office of Cancer Control and Prevention in the Department of Health. New Jersey may be one of the first States to secure funding for this particular activity through the State appropriations process.

All of the State’s cancer control activities are conducted in partnership with numerous stakeholders, including the Eastern Division of the American Cancer Society; the State’s medical schools; the new School of Public Health, the NCI-designated Clinical Center at the Cancer Institute of New Jersey; survivor groups; public health professionals; and others who have an interest in controlling cancer.

Thirteen percent of New Jersey’s population lacks insurance, and a recent study suggests that the number of uninsured is growing. New Jersey provides approximately \$700 million of “charity care” (reimbursement for otherwise uncompensated care). Some of that care includes cancer treatment. The State legislature appears to be close to passing legislation to participate in the Breast and Cervical Cancer Treatment Act provisions. Tobacco Settlement dollars are providing Family Care Programs for Health Insurance to about 125,000 adults in New Jersey who fail to meet the eligibility requirements for Medicaid.

Until December 1999, most managed care plans in New Jersey would not provide coverage for routine care for people enrolled in cancer clinical trials, which discouraged individuals from entering trials.

Insurance coverage does not necessarily ensure that people receive care consistent with evidence-based recommendations. For example, in 1999, only two-thirds of eligible women enrolled in commercial HMOs in the State had received a mammogram or a Pap smear within the preceding 2 or 3 years, respectively. Similarly, a recently published national study in *The Journal of the American Medical Association (JAMA)* found that only 50 percent of New Jersey women with Medicare benefits had received a mammogram in the preceding 2 years, compared with somewhat higher rates in adjacent States and nationally.

Key Points

- The possibility of universal health insurance usually means payment by the Government, but the support needed to ensure that everyone has health coverage may not all have to come from the Government.
- Culturally appropriate risk-reduction strategies are needed. Health providers must be taught to apply those strategies to the population in a competent manner.
- More effort is needed to encourage people to take advantage of cancer risk-reduction opportunities, including those people with health coverage.

MS. ANN MARIE HILL

Background

The New Jersey Commission on Cancer Research was one of the first agencies in the country created to promote and support cancer research at the State level. Initially, the Commission funded research grants and fellowships. It recently broadened its approach, attempting to bring the benefits of the Nation's fight against cancer to New Jersey citizens.

Key Points

- The Panel has asked the speakers to consider difficult questions about some of the complex realities of life. The answers, when we find them, may require a major commitment to change at all levels.
- Working with many partners in the State, including the Cancer Institute of New Jersey and the American Cancer Society, the Commission is trying to improve access to cancer clinical trials, for which the routine clinical costs are now reimbursed statewide through a voluntary agreement among New Jersey's 10 major health insurers—including 98 percent of the HMOs, self-insured plans, and Medicaid. Together with the Medicare policy on clinical trials now in effect, New Jersey has the most comprehensive insurance coverage for clinical trials in the country. This has been an important step forward, and it was achieved through cooperation, communication, and intensive discussion of every issue. In this way, consensus was brought to a complex health issue, and the success of this effort bodes well for attempts to solve other health problems.
- The Commission discovered that little information existed about local clinical trials. Since 80 percent of patients are treated in the community, it is essential to have clinical trials at the community level. In New Jersey, 50 percent of hospitals offer clinical trials, but there was no organized way of finding out what trials were available in a given community. The Commission and its partners approached the NCI's PDQ program, which worked with the State to expand the information available about clinical trials in PDQ that are available for New Jersey. Today, patients in New Jersey can search PDQ and find clinical trials offered in New Jersey, a local physician offering any particular trial, and a phone number with a "real person" who will tell them about that trial. The Commission believes this has been an important step in making clinical trials more accessible to people.
- The limitations of these programs are that a person must be insured and have computer access. New Jersey is well aware that many people cannot meet either condition. The next step will be to work to expand insurance coverage and create community links so that communities and individuals who do not have computers can get this information.
- In collaboration with advocates, scientists, and patients, a program of open forums called *Sharing Perspectives: Cancer Researchers Reaching Out to the Community* has been established to try to address the issue of trust. Researchers, advocates, the public, and the community meet to share ideas and discuss the gaps between research and what is happening at the community level. Through these forums, participants try to deal with misperceptions and biases and find common ground. Those who are indigent are provided with transportation and a means to participate in the program. Though a small step, it is moving toward a better understanding of some of these problems.
- New Jersey has a diverse Latino community that includes Puerto Ricans, other Caribbean Islanders, South Americans, and people of Mexican descent. However, many studies and programs in the Latino community are based on Mexican populations and may not be effective. Recognizing that incorrect assumptions about the similarity of cultural beliefs can be a barrier to care, New Jersey has started to conduct focus groups, surveys, and interviews with the subcultures within its ethnic groups to determine if people from different subcultures can be reached with the same message. This effort is

limited to the Latino community; it is, however, recognized that a similar effort is needed for other racial/ethnic populations. For example, do southern blacks have the same cultural issues as blacks from the various Caribbean Islands? New Jersey has large populations that are black, but they may have different cultural issues. The issue is even more complex concerning the State's Asian and Pacific Islander populations, who have diverse dialects and subgroupings. The School of Public Health is helping to address these cultural sensitivity issues.

- Recruitment is most difficult for prevention trials. New Jersey is experimenting with a community advocacy model to help with recruitment to the Study of Tamoxifen and Raloxifene (STAR trial). The advocacy community and cancer survivors can play a critical role in helping to bridge the gap between dealing with the research community and bringing the best care to the public.
- Perhaps New Jersey's greatest strength is in collaborating with stakeholders to solve problems; this has been particularly true in advocacy and cancer policy. The State has the strongest Genetic Privacy Act in the country. Last year, five major pieces of legislation on pain and palliative care were passed by the legislature. This has occurred because of strategic collaboration as well as desire. Summits have been held on prostate and breast cancer. A forum was held to listen to the community concerning its needs and how they should be addressed in a comprehensive cancer plan.
- Measuring success is difficult. Ms. Hill recounted her recent experience at a support group in the inner city of Newark. After a lively discussion about progress in cancer research, Ms. Hill asked the group how the research community could make citizens more comfortable working with researchers and participating in research. A support group participant noted that she and others in the group had recently attended one of the "Sharing Perspectives" programs. Afterward, they took the bus home. The next day, this woman waited 4 hours in the clinic for her chemotherapy, then made the trip home. By the time she arrived home, she was so ill she could only crawl into bed, where she remained alone for 3 days with no help. For her, this is the reality of cancer care today.
- Sometimes we tend to "put Band-Aids[®] on hemorrhages." We pretend we know the answers when we do not. We make assumptions that everyone fits into the established "boxes." A new paradigm is needed: one that is open, integrated, multicultural, and sensitive.

MS. EVELYN ROBLES-RODRIGUEZ

Key Points

- It is imperative that clinical trials be made available in languages other than English (such as Spanish, which is rapidly becoming a second language in the United States) to enable many minorities to take advantage of clinical trials.
- The underserved in New Jersey include the uninsured; those with low socioeconomic status; minorities who may not know how to access care because of language and other barriers; and the homeless, who, because they lack a permanent address, may not be able to get the followup care they require.
- One of the chief barriers faced by the underserved is fear. This includes fear of the disease itself; many equate cancer with death and, therefore, do not want a screening test that may tell them they will die in the near future. There is also fear of a positive diagnosis. A number of patients in the program get screened, but when they find out they have an abnormality, they refuse any followup care. Because of existing myths in the community about cancer treatment, many patients are diagnosed and then refuse some of the treatment they need. People also fear the social and financial consequences of having cancer. For example, a 55-year-old Hispanic woman with advanced breast cancer refused her chemotherapy because she was the primary care provider for her grandchildren;

she did not want to be unable to care for them because she was suffering the side effects of chemotherapy.

- Other barriers include lack of knowledge (many women and men in their 60s have never heard of prostate screening or colonoscopy, for example), lack of physician referral for screening, and distrust of the health care system. Some minority and poor patients have been treated in a demeaning manner when they have gone to the hospital for care.
- Language barriers are significant, as are cultural barriers. For example, cultural barriers prevent men from getting the much-needed digital rectal exam because they find it embarrassing. Religious barriers keep some patients from getting cancer screening because they fear that if they are screened, it shows a lack of faith in God. Poor patients face a host of socioeconomic barriers to screening.
- Community-based programs that are trying to reach these patients also face many barriers. Even when programs are provided free of charge, people are not flocking to them. It takes a lot of labor, love, and care to get people to come in for screening. Often, nontraditional outreach is needed, and programs have to devise this on their own based on the population's composition and needs. It is important that workers are culturally similar to the target population and that both understand the community and have the necessary language skills.
- Community trust is very important in order to convince people to be screened, and unfortunately, because many community programs are competing for funding and do not have a lasting presence in the community, this trust often is not established.
- The Camden County Cancer Screening Project has tried a number of innovative outreach efforts to the community. One of these is *Where's Shirley?*, a play geared toward educating African-American women about breast cancer and encouraging screening. A similar play, entitled *El Secreto de Marta*, has been developed in Spanish for the Hispanic population. A third play, called *Catching Debbie's Star*, or *Debbie Knows*, educates the public about clinical trials and tries to encourage women to participate in the STAR trial. The screening program has also conducted home parties in the style of Tupperware® parties; attendees are provided refreshments and breast and cervical cancer education, then encouraged to be screened as a group.
- The program has also mailed postcards to people and encouraged them to share the postcards with others who might need free screening. One of the program's most successful ventures was a mobile mammography unit in which mammography screening, prostate screening, and cervical screening were provided in the community. Unfortunately, due to monetary constraints at the local hospital, the mobile unit was lost. Access was lost for many patients who had never been screened in the past, and who were eager to be screened through the mobile unit.
- The screening program has been partnering with some of the homeless programs because they are more experienced at tracking this population for needed followup.
- The program has also worked hard to include community leaders—particularly cancer survivors, who are one of the most important keys to showing people in the community that cancer is not a death sentence.
- Focus groups made up of minority women pointed out that few support programs exist for women of color. In addition, the program has involved the churches to try to address some of the barriers in the community. A church-based nurse training program was conducted, enabling those trained to become active in the health care of their church members and serve as liaisons between the churches and the health care system.
- The program has been trying to educate community health care providers to make them aware of the importance of referring patients for screening and of the importance of these screenings.

- Education is perhaps the most important way to overcome some of the barriers to care. Education must be culturally and linguistically appropriate. It may be necessary to devise innovative ways of reaching the target communities. Drama is an excellent way to reach people who are hard to reach and who may not be interested in didactic education. Cancer awareness at the high school level is an excellent way to not only open pathways to dialogue between parents and children, but to try to promote early intervention (e.g., smoking cessation and prevention) at a time when it will have a significant impact.
- Funding is needed to continue programs that have established trust in the community. The importance of funding for outreach personnel cannot be overemphasized. Mobile mammography units and mobile health units are excellent ways to reach people where they live, work, pray, and play; these should receive greater funding.
- There must be coverage for people with positive diagnoses. Although an avenue now exists for coverage of people who have been diagnosed with breast and cervical cancers, there is no such funding for people with other cancers. It is cruel to go out into a community and diagnose people with a cancer and then leave them on their own to find sources of treatment.
- Hospitals are taking many charity care cases, but the more charity care funding is cut, the less probability there is that these hospitals will be able to stay open and provide the quality care they have been trying to provide in their communities.
- The CEED programs have been quite efficient in reaching the underserved; it is important that their efforts continue to be funded.

DR. DEAN R. PRINCE

Background

Dr. Prince, age 35, is an equine veterinarian. Three years ago, while teaching at the University of Edinburgh in Scotland, he let his private insurance in North America lapse because he felt he was well covered by Great Britain's National Health Service. In June 2000, he was diagnosed with stage IV colorectal cancer. He had surgery to remove part of his colon and 35 abdominal lymph nodes, two-thirds of which were found to be cancerous. He still has three enlarged lymph nodes on his neck. To date, his major organs have been unaffected.

Though he could have been treated in Great Britain, he was advised to return to the United States, both to be with his family and because he could access better health care at home. He expected that he would be able to join the Group Insurance Trust (group health plan) of the American Veterinary Medical Association, of which he was a member. Members are entitled to join even with preexisting conditions; however, those with preexisting conditions can be excluded in about six States, of which New Jersey is one. Thus, Dr. Prince returned home without any health insurance. He was left with little choice but to apply for Supplemental Security Income (SSI) and Medicaid. Since he had been diagnosed with a terminal disease and was not expected to live long, he was accepted immediately. He was also fortunate that the hospital at which he was receiving care provided a third party to complete all necessary paperwork. He had only to sign the completed forms. Dr. Prince noted that SSI allows a person to have only \$2,000 in assets. Having lived a somewhat adventurous life since leaving school, he had not accumulated many assets; had he done so, he would have had to sell everything in order to apply for assistance.

He was allowed a benefit of \$397 a month. However, he was also required to apply for Social Security Disability Insurance (SSDI), which is based not only on disability with a terminal disease, but also on the amount an individual has paid into the system (20 credits over 10 years). Again, the application process

was managed for him by a third-party agency. The SSDI benefit provides for about 42 percent of a person's average earnings over the previous 10 years. However, Dr. Prince soon learned that once a person is on SSDI, he or she suddenly loses SSI and Medicaid coverage. In Dr. Prince's case, he was on Medicaid for 60 days, then got a letter saying that he had been granted SSDI, and his Medicaid coverage was terminated. The letter went on to say that he would be provided Medicare coverage, but not for 2 years.

Having no other options, he sought care through the new New Jersey Family Care Program, which is funded with monies from the Tobacco Settlement funds. However, to be eligible, one's maximum income can be only \$696 a month. Since he had worked hard when he was working, Dr. Prince's SSDI benefit was about \$925 per month, and he was not eligible for the program.

Finally, he was accepted into the State charity care system and feels he is better off without an insurance company. He is receiving good care, has good doctors, and is not being excluded from any sort of treatment. Currently, he has no medical bills, although his care in the past year has cost between \$70,000 and \$80,000. The charity system covers hospital room and board, medications in the hospital, catheters, and nursing and related care, but it does not cover laboratory fees, prescriptions, or doctor's fees. Dr. Prince indicated that he has been fortunate that his doctors have elected to waive their fees, and his prescription costs have been minimal. He noted that he has been using marijuana to control his severe chemotherapy-related nausea and that it is far less costly than the \$20 a day for the prescription pills that do not work as well.

Dr. Prince is hoping to be referred to the NIH to participate in a clinical trial.

Key Points

- There are misconceptions about the attractiveness of socialized health care such as the national plan in Great Britain. It is not free—9 percent of each person's income is withheld to pay for it—which is probably about equal to the cost of private health insurance in the United States. Everyone has equal access, and there are very good doctors, but there also are long lines because of limited system resources. Dr. Prince believes it took much longer to be diagnosed in Britain; it was almost a month after he knew he had a poorly differentiated adenocarcinoma in his neck before he was able to have a CT scan, a colonoscopy, and other tests needed to locate the primary tumor. A wait of such duration is hard to endure when you know you have cancer.
- People ask how the Federal and State governments are going to fund health care for people, but the private insurers need to be held more accountable for their part. Most of the money used to fund health care in this country is being filtered through the insurance companies. The people may be knocking on the back door of the White House while the insurers are already inside. The system may be so politically controlled that it will be difficult to change.
- The application processes for Federal assistance require extensive medication information, medical record copies, laboratory results, and a work summary for the past 15 years. This level of documentation is difficult for most people to produce. Perhaps all patients need a third party to represent them and expedite this process.
- Unlike the Federal health care assistance programs, the New Jersey charity care system allows a person to have a job and earn up to \$17,000 a year without affecting benefits under the program.
- Dr. Prince noted that as a white male, he is a minority among the patient population at the hospital at which he is being treated and has spent 60 days over the past year. It is his impression that all patients are receiving equally good care.

- Self-education is essential. Patients who take a passive, “wake me up when it’s over” attitude are likely to do less well than those who are more assertive. Fortunately, Dr. Prince was well educated and familiar with Internet resources such as Medscape, Medline, and PubMed, which enabled him to access newly published literature on his disease. Doctors can also be very helpful, but they are busy and can only be burdened so much in terms of providing information to patients.

MR. KEVIN P. McCARTNEY

Background

Mr. McCartney is a metastatic melanoma patient. For a few years, his wife had been telling him that there was an odd-looking mole on his back. Since he could not see it, and the mole was no larger than a pencil eraser, he ignored her. In April 1996, however, Mr. McCartney’s wife showed him a story in *Good Housekeeping* magazine about melanoma. The story included a photo of a cancerous mole; this, she told him, was what he had on his back. Mr. McCartney immediately made an appointment with a dermatologist; 2 days after the appointment, he received a diagnosis of melanoma. Mr. McCartney noted that in spite of his being a 45-year-old, successful, and well-educated person, his initial source of cancer information had been *Good Housekeeping* magazine.

The dermatologist performed a radical excision. Additional cancerous material was found, and he was referred to a melanoma specialist at Thomas Jefferson University in Philadelphia who recommended that the lymph nodes be removed from Mr. McCartney’s left armpit. In July 1996, 55 lymph nodes were removed, and all were negative. In November 1996, a lump appeared on the right side of Mr. McCartney’s neck. The original lesion had been on the left side of his back. Mr. McCartney’s physician informed him that the only FDA-approved course of action was massive doses of interferon, but that he was not optimistic about the outcome. Mr. McCartney’s prognosis was downgraded significantly, and he was told to prepare for the worst, with 1 year being an optimistic expectation for survival. He was also told that the last 6 months would not be pleasant.

Mr. McCartney and his wife began a frantic search for an experimental treatment, searching the Internet day and night. His physician informed Mr. McCartney that he would not qualify for any vaccine clinical trials due to the contralateral metastases. Through his research, Mr. McCartney discovered a vaccine program at the John Wayne Cancer Institute in Santa Monica, California. His physician was aware of the program. He cautioned Mr. McCartney, however, that the cost would be astronomical, and the results for advanced disease were not especially good. He also strongly cautioned Mr. McCartney about grasping at straws in cancer research and warned that immunotherapy required multiple trips. The doctor told Mr. McCartney that he would recommend the program if it were in Philadelphia, but it was difficult to recommend a program that could bankrupt a patient and that still had not been proven effective. At the end of a 3-hour consultation, during which Mr. McCartney was never rushed, the doctor agreed that the best alternative was to go to John Wayne.

In February 1997, Mr. McCartney and his wife flew to California, where he spent 10 days going through tests and observations. He was accepted into the program. The initial trip cost was \$5,000, and he had to pay \$2,000 for the experimental vaccine. A 5-year treatment plan was developed, and Mr. McCartney received his first eight injections of vaccine. For the first 3 months, he had to travel from New Jersey to California every 2 weeks. The vaccine took its toll, and combined with the jet lag, produced in Mr. McCartney a constant state of nausea and fatigue. The McCartneys traveled monthly to California for the balance of the first year. In the second year, they traveled to the John Wayne Institute every 2 months; in the third year, every 3 months. Seven days after each trip, his blood was drawn and spun, and he kept the serum in his freezer at home. On each trip, he had to take the serum along in an ice chest.

Mr. McCartney characterized his care as “fantastic.” He looked forward to his appointments for the mental uplift they provided. Unfortunately, at the end of 3 years, and after 180,000 air miles, his treatment was abruptly stopped. His doctor indicated that the Institute was starting a Phase III trial with the vaccine and that the Food and Drug Administration (FDA) required that all nontrial patients be discharged. He tried to reassure Mr. McCartney, telling him that he had achieved maximum immunity and should just come back for annual checkups. He also told Mr. McCartney that he would give him the vaccine if he became ill again. In February 2001, however, during his annual checkup, he was informed that the FDA would not permit off-trial use of the vaccine again.

Predictions about the economic impact of the travel associated with his treatment were correct. Mr. McCartney had to close his business and liquidate all his assets to keep his family intact. His normal oncology expenses were covered by insurance, but his clinical trial and travel expenses were not. His wife became his full-time travel consultant and secretary. She spent her days combing the Internet to find any information that would help minimize their costs and spent many hours haggling over car rentals and frequent flier blackout periods and trying to schedule Mr. McCartney’s appointments between hotel conventions so that rooms would be available. Mrs. McCartney also became a resource for other John Wayne patients and freely offered information and tips to help other travelers. Mr. McCartney noted that she taught other patients the fine art of begging for help, an art critical for cancer patients in this country. In addition, friends and family donated their frequent flier miles. Mrs. McCartney discovered a United Way program that provided one airline ticket from Delta Airlines every 6 months. Continental Airlines gave one ticket each quarter. Periodically, Mr. McCartney could get a free hotel room provided by Westin Hotels through the American Cancer Society, and DoubleTree Hotels provided rooms at reduced rates. Finding these programs and cost-saving opportunities took an extraordinary amount of work and research. Neither Thomas Jefferson Hospital nor John Wayne Cancer Institute had any mechanism for helping patients who must travel.

Mr. McCartney noted that while he and his family made plans for his death, they were unprepared for the problems faced by cancer survivors with society and employers should they survive. The frequency of his treatment-related travel and the mental strain of the experience prohibited Mr. McCartney from working during the first year. He tried to maintain a part-time work schedule during the subsequent years, but it was difficult, since he had to take a week off each time he went to California. The family’s savings dwindled, and the financial stresses grew. During this time, the McCartneys tried to insulate their children from the experience of the disease by attempting to maintain normality in their lives. Despite their financial situation, they managed to pay for two college educations.

Although Mr. McCartney holds an advanced degree from a prestigious university and has extensive work experience, every job interview focused on the gaps in his employment and part-time work over the previous few years. Mr. McCartney noted that if the word *cancer* comes up in an interview, that interview is over, regardless of any laws. He wrote personal letters to elected officials explaining his employment situation but received either no response or a conciliatory letter. He is still looking for a job.

Mr. McCartney noted that he had the resources to travel for treatment, but wonders what he would do if he found himself in a similar position again, now that those resources are gone.

Key Points

- Many people still consider melanoma a curable skin cancer. In fact, there is no cure. One American dies every hour from melanoma. It is the number one cancer for women between the ages of 25 and 29 and the number two cancer behind breast cancer for women between the ages of 30 and 34. It does not respect age and is often found in very young children. It does not respect race. For example, Jamaican singer Bob Marley died of melanoma at the age of 36. Everyone should go to a

dermatologist and learn how to do a self-check for melanoma and devote 15 seconds every day to doing that inspection.

- Hopefully, the Panel will address the issue of costs incurred by patients who must travel to receive care. Similarly, the employment issues faced by cancer survivors need to be addressed. There is no source of employment assistance for survivors.
- A cure for cancer is elusive, but finding a way to care for cancer survivors and their families is not. This is the side of cancer we can fix now. The President and Congress need to do something to make proper care available to everyone so this American tragedy does not continue.

MS. JANET A. HARRIS

Background

Ms. Harris was diagnosed with rectal cancer in February 1999. Her family has a strong history of cancer; Ms. Harris' father died from esophageal and stomach cancer, her mother from rectal cancer, and her sister from colon cancer. It was her mother's death that caused Ms. Harris to become more aware of rectal cancer, the possibility of a hereditary component in this disease, and the consequences of not being tested.

At the same time, Ms. Harris was reluctant to seek medical attention because of the insensitivity with which her mother had been treated by health care professionals during her illness and the failure of doctors treating her sister (who also had multiple sclerosis) to fully inform her about her cancer. She believes that had her sister better understood her condition and the need for treatment, she might not have died.

Following her sister's sudden death, Ms. Harris decided she had to find out if she, too, had cancer. Though she had been experiencing rectal hemorrhaging for several months, she had no health insurance. This factor, in addition to her other hesitations about the health care system, had kept her from seeking care. Friends and family suggested she investigate the possibility of charity care, but because of the stigma associated with the word *charity*, which in some minority communities is essentially synonymous with *welfare* or *public assistance*, she was reluctant. Ms. Harris refused to expose herself to what she assumed would be a demeaning experience. However, in need of a medical procedure, she finally did apply for charity care. She was diagnosed with rectal cancer. Contrary to her fears, she received excellent treatment from caring doctors.

Because she was provided with the information she needed to participate in her own care, Ms. Harris found she also was able to be of help to other patients who were less informed and more afraid. She urged all patients to empower themselves by becoming informed.

DISCUSSION—STATE OF NEW JERSEY

Key Points

- Universal access does not automatically equate with Government pay or any single-payer system. Health care is never really free; ultimately, someone pays—usually employers or citizens via taxes—yet the consensus of speakers is that someone has to pay for at least a minimum level of care for all in this country.
- In order for clinical trial costs to be covered in New Jersey, the trial must be approved by NIH, the Department of Defense (DoD), or the Veterans Administration (VA) or as an FDA Investigational New Drug/Device (IND). Ensuring recognized national oversight for safety and monitoring was a key

element in successfully working out an agreement with the State's major insurers, because they felt confident that the types of trials in the approved categories were sound and scientifically based.

- Dr. Bresnitz indicated that the breast and cervical cancer screening effort has been evaluated in terms of numbers of cases detected compared with number screened. It appears that cases are being detected at earlier stages than before the screening program, but later-stage diagnosis is still more common in minority populations. The effectiveness of the prostate and colorectal cancer screening programs, each only about a year in operation, has not yet been evaluated.
- Dr. Prince believes that his basic medical knowledge was of great help to him in interpreting information he found on the Internet, and he recognized that his level of education and computer familiarity are considerably greater than those of many other cancer patients. He indicated that the independent third party (paid for by the hospital) who assisted him with his SSI and other applications was of great help. He also noted that it is in the hospital's interest for patients to be approved quickly so that the hospital can start receiving reimbursements for care provided. Consistently applied mechanisms are needed to help inform people of the benefits for which they may be eligible.
- Dr. Prince also reiterated his belief that health insurance companies should be held accountable for providing affordable coverage. He noted that he would like to work as long as he is able but will jeopardize his benefits if he does. If he had affordable insurance, this would not be the case. He feels he has little choice but to use the system according to the rules that have been set. Further, he suggested that the high cost of care is due in part to the allocation of resources such that much of the money goes to the intermediary—i.e., the insurer—rather than the providers of care. It should be possible to strike a balance between a Government-controlled health care system, which could subject people to an even greater volume of paperwork, and the current private system.
- Mr. McCartney clarified that the vaccine he received was not administered under the auspices of a clinical trial. The John Wayne Cancer Institute had been giving the vaccine for 13 years to anyone who wanted the treatment. However, statistics had not been published on its efficacy. When the FDA-sponsored trial was initiated, Mr. McCartney and the other 1,500 patients who were receiving the vaccine could not participate in the trial and could no longer be treated.
- In New Jersey, former Governor Whitman and current Acting Governor DiFrancesco set the policy on use of the Tobacco Settlement funds: All of the money was designated for health care-related purposes. While other States still have not developed a plan for using their Settlement funds, New Jersey developed a spending plan immediately, devoting significant amounts to tobacco-related activities.

TOWN MEETING MAY 24, 2001

In addition to the scheduled testimony presented on May 24 and 25, 2001, the President's Cancer Panel held a Town Meeting to solicit input from the public on issues and problems in obtaining cancer information and cancer care. The public was invited to attend the Town Meeting to raise questions and share personal experiences. Dr. Harold Freeman, Chairman, represented the Panel. Dr. Maureen Wilson, the Panel's Executive Secretary and an Assistant Director of the NCI, and Dr. Jon Kerner, Assistant Deputy Director for Research Dissemination and Diffusion, Division of Cancer Control and Population Sciences, NCI, were also in attendance. The meeting was moderated by Dr. Elmer Huerta, Director and Founder, Cancer Preventorium, Washington Cancer Institute, Washington Hospital Center, Washington, DC.

INTRODUCTION—DR. HUERTA

Dr. Huerta welcomed the participants and explained the composition and role of the President's Cancer Panel. He noted that this is the last in a series of seven regional meetings and summarized some of the issues that have been raised to date: the impact of poverty on people with cancer; difficulties in navigating the health care system; issues related to distance from health care providers and facilities; lack of information and education; and cultural perceptions about cancer and cancer treatment.

OPENING REMARKS—DR. FREEMAN

Dr. Freeman described the impetus for the current meeting series and invited participants to tell their personal stories and share their opinions as to why people do not receive the most appropriate cancer care. He emphasized the importance of hearing from real people who have real problems. He also thanked Dr. Huerta for moderating the Town Meeting and noted his contribution, particularly to the Hispanic community, in communicating cancer information over the past several years.

Key Points

SUSIE MILLER, CHESAPEAKE, VIRGINIA

- Ms. Miller's husband has carcinoid syndrome. As his caregiver and advocate within the health care system, she has found that it is not enough to be proactive; one must be aggressive. This is particularly true to get needed referrals, make sure that appropriate testing is actually done, and ensure that all members of the treatment team receive and read copies of test results. She noted that she usually has to ask for copies of test results; they are seldom provided to her. She advised other patients to manage such information flow themselves rather than expect that providers will take care of it. Ms. Miller believes that all cancer patients must have a family member or some other person looking out for them or they will not get appropriate care. Since some patients do not have a family member to advocate for them, a Patient Coordinator or Navigator system such as that described by the representative from Christiana Care in Delaware should be available to patients.

JARVIS KUO, NORFOLK, VIRGINIA

- Mr. Kuo, now age 26, was a child recently immigrated with his family to the United States when he was diagnosed with osteogenic sarcoma. Because none of the family spoke English, translators were needed to help explain Mr. Kuo's test results, treatment, and other medical information. Since the

hospital had no translator, friends of Mr. Kuo's parents would take off work to help translate at medical team meetings and at other times. However, despite their best efforts, meanings were lost in translation, and some parts of the dialogue were missed. This was very stressful for Mr. Kuo's parents, because they could not understand what was happening to their son. Though they had a social worker, they were not told about advocacy or support services that might be available to them. In time, Mr. Kuo's English skills became good enough that he himself became his parents' interpreter, which was highly stressful for him.

Dr. Huerta referred to the situation described by Mr. Kuo as *linguistic isolation* and noted that this problem is common in the Hispanic community. He also noted that with immigrant Russian families, children would come in to translate for their parents; the inadequacy of the situation was obvious.

ELNORA MARSH, MIFFLINBURG, PENNSYLVANIA

- Ms. Marsh is a 12-year survivor of breast cancer. She has also had surgery on her cheek for an apparent skin cancer. She believes she may actually have carcinoid syndrome. Some doctors, she feels, are not sufficiently suspicious of or investigate fully the symptoms patients report. In her own case, she complained for years of pain; by the time her cancer was finally diagnosed 4 years later, she had two massive tumors. She has had to become aggressive to get the care she needs and is no longer content to wait when doctors are not appropriately concerned about her symptoms. She noted that under the current health care system, patients are rushed out of the doctor's office and almost have to refuse to leave and demand care to avoid being dismissed.

CONCEPCIÓN ROJAS, WASHINGTON, DC

- Ms. Rojas was diagnosed with breast cancer 3 years ago. She had just come to the Washington metropolitan area from Florida and did not know where to turn for help. She found out about a community program but was ineligible because she was under age 50; however, she persevered and was eventually approved. She received good care and is thankful for the people who helped her at a difficult time in her life. She has seen friends die of cancer because of lack of information and lack of programs for people of all races and cultures. She implored the Government not to take away funding for cancer treatment for the poor, who may receive initial treatment, but then cannot afford medications, resulting in incomplete treatment.

WILLIAM OROZSCO

- Sixteen years ago, Mr. Orozco was diagnosed with non-Hodgkin's lymphoma in his small intestine. He underwent surgery, followed by 6 months of chemotherapy. He remained disease-free until several months ago, when he was diagnosed with a recurrence in his stomach; he is again receiving chemotherapy. Since he has no medical insurance, he has accumulated considerable debt related to his care and does not know how he will repay it. He noted that the doctor who treated him initially has never charged for his services, for which Mr. Orozco is most grateful. Mr. Orozco has struggled to pay for his other care. For example, his family helped him pay \$500 for an endoscopy he needed, but many other Hispanics have no family to assist them with treatment costs. He is now trying to obtain Medicaid approval. Mr. Orozco emphasized the importance of public education efforts, such as Dr. Huerta's television show, that encourage people to be tested and to seek care when they have symptoms.

ANNA BONILLA, WASHINGTON, DC

- Latinos in the Washington, DC, area need help to control cancer in their community. The community suffers due to fear and lack of information. This is due in part to linguistic isolation. More prevention centers are needed, as are community leaders and navigators to help people overcome barriers to care.

DAVID DALTON, SUITLAND, MARYLAND

- Mr. Dalton was treated for non-Hodgkin's lymphoma 22 years ago. He received his treatment through the VA system and was entirely satisfied with his care. However, he was unable to work for a period of time and was forced to live with his parents in another State while his wife and children lived on welfare and the Social Security income he sent them. For some years, he received his regular followup care through VA facilities. Recently, however, he experienced diarrhea for several weeks, and despite numerous visits to doctors at the HMO to which he now belonged, his condition did not improve. Through a routine chest x-ray, he was eventually diagnosed with lung cancer. Mr. Dalton indicated that he never knew, and was never told, that his symptoms could be related to lung cancer. The financial stresses associated with his cancer have been very hard to endure. Currently, he has been out of work for 8 months. He applied for 100 percent disability through the VA but was told it takes a year to process a claim. Mr. Dalton expressed frustration at this delay, since all of his records and doctors are at the same location and should be easy to access.

KAREN CONNELLY, RICHMOND, VIRGINIA

- As one who has made a 40-year career of public health nursing, Ms. Connelly knows full well that when a breast lump is found in a woman, it is necessary to beg, borrow, steal, and do anything possible to find someone who will do a mammogram if she is uninsured and not eligible for Medicaid. Ms. Connelly also noted that she has had a lot of cancer in her family and has cared for many of those family members in her home. She is a nurse case manager in her work and has acted in this role for family members. She suggests that all patients need nursing case management, and that it is one of the solutions to the problems of access to and continuity of care. Ms. Connelly added that it is not just the poor who lack access to appropriate care; she cited the case of a financially well-off neighbor who was having gastrointestinal problems. This neighbor was treated for 18 months by her HMO primary care doctor without referral to a gastroenterologist. Ms. Connelly insisted she see a specialist; when she did, she was diagnosed with stage III colon cancer.

DR. CHARLES GABE, PRINCETON, WEST VIRGINIA

- Dr. Gabe is a radiation oncologist in southern West Virginia, having practiced there about 10 years. The area is semirural. The stories told by patients, family members, and health professionals at this meeting are consistent with the experience of many patients in his area. If health care professionals would take the time to give patients a kind word, go the extra step, and pick up the telephone and try to facilitate their cases for them, it would make a major difference. Dr. Gabe noted that he has experienced cancer in his family and knows how fortunate he is to understand the system and how to manipulate it. Those who do not speak English have an exceedingly hard time navigating the system; the country needs to do something to correct this problem. NCI should promote more strongly the Cancer Information Service (1-800-4-CANCER) and CancerFax, which are available in English and Spanish. The information covers every cancer site and is current.

Patients may have delayed diagnoses because their physicians are too busy to take a detailed history, or because they dismiss the patient's complaints of aches and pains when in fact they could be due to bone metastases. As a society, we need to change our whole outlook on the system. Physicians and other health care providers need to take the view that they were blessed with the ability to help people and to be in this field. They owe it to the community and to society to better serve patients and help them through the health care system.

TRINIDAD AYQUE, WASHINGTON, DC

- Ms. Ayque is a single mother of a 12-year-old son. She has prided herself on being self-supporting and not asking for any kind of public assistance. In 1993, her gynecologist told her she had cervical cancer but indicated that it was at an early stage and not to worry. Not having a lot of knowledge about health and not understanding the seriousness of a cancer diagnosis, she took no action. Years passed, and her abdomen was becoming distended. Ms. Ayque went to another doctor, who told her she had a tumor the size of a tennis ball. Ms. Ayque, who does housecleaning for a living, was uninsured, and her only savings was money she had put aside for her son's college education. Since she was not in any pain, she again delayed treatment. Later, she went to another doctor, who told her she needed an operation. She wanted to get family health insurance but could not afford the premiums. Finally, 2 years later, she took her son's college money to Peru (where she was born), and had the operation there because the cost was about one-fourth (\$7,000 vs. \$29,000) what it would be in the United States. She did not want to go to the hospital in the United States and then have a large medical debt to try to repay.

Ms. Ayque applied for the Child Health Insurance Program (CHIP) for her son but was denied because her income was \$250 per month over the income ceiling. As long as she works, she is not eligible for Medicaid. At this time, she does not know what to do. She is having severe pain in her arms, but medications prescribed for her are not helping. Ms. Ayque wishes there were affordable health insurance for people like her who do not want to live on public assistance and want to be self-supporting. She had hoped that the Clinton health proposal would pass and make insurance affordable for people like her. She is now receiving followup care at a low-cost clinic in suburban Virginia.

UNIDENTIFIED FEMALE SPEAKER

- The Latino community is often hesitant to ask for help. Many Latino immigrants were professionals in their home countries but had to take menial jobs when they came to the United States. Many leave their families behind and come here to work, often 12 to 14 hours a day. Still, when they are sick, they have insufficient income to pay private doctors. When they ask for help, they often cannot document income because their salaries (e.g., from housecleaning) are seldom paid by regular payroll checks. Since they have no pay stubs to present to the clinic, they do not qualify for assistance. Many in the Latino community wait too long to go to the doctor because of lack of information. However, the Hispanic people understand the importance of prevention. More prevention information and prevention centers are needed. The Latino community works hard, pays taxes and rent on time, and does not want government assistance. The community wants to be independent and self-sufficient, but help is needed in the area of health care.

DR. GABE

- The U.S. Public Health Service sends students through medical school and requires them to pay back their indebtedness by serving communities in need of medical care. However, one seldom hears about this program anymore. If it has been discontinued, perhaps it should be reestablished.

DR. HUERTA

- Dr. Huerta noted that in Peru (his country of origin), doctors must spend at least a year after finishing medical school working in poor areas before they can receive their diplomas. He began his career providing cancer chemotherapy but found that many of his patients had cancers that could have been prevented or detected earlier, and that the principal problem was lack of information. In 1986, he realized that it might be possible to sell health messages through the media in the same way that

entertainment messages and products such as tobacco and alcohol were marketed. He began using radio, television, and the Internet to communicate prevention messages to the community. He also asked himself whether it would be possible to have a prevention center at which healthy people could get education and screening. Since that time, cancer prevention has been his main career focus.

DR. GABE

- Once patients are diagnosed with cancer, if they do not qualify for any programs and are uninsured (e.g., the working poor), they should automatically qualify for either Medicaid or Medicare, with funds earmarked specifically for treatment, followup, and surveillance of their malignancies. To pay for this care, people who can afford it should be required to pay higher Medicare premiums than those with lower incomes. Likewise, a prescription drug plan could be implemented so that cancer patients would automatically be covered for cancer medications. Dr. Gabe noted that West Virginia is trying to pass a bill to participate in the Breast and Cervical Cancer Treatment Act, but he is disturbed that only women diagnosed through the CDC screening program will be covered.

DR. KERNER

- It is important to realize that at its current funding level, the Breast and Cervical Cancer Screening Program covers only about 14 percent of those eligible. As a society, we have to communicate to our legislators that resources have to be made available to expand eligibility, because if the Breast and Cervical Cancer Screening Program were covering 50 to 100 percent of the eligible population, and treatment funds were available through the Breast and Cervical Cancer Treatment Act, the problem described would be solved. Thus, the fundamental dilemma currently is that we spend enormous resources on finding out what we need to do to either prevent or cure cancer, but we are not spending comparable amounts to make sure that these discoveries reach the public. Dr. Freeman has made clear through his hearings and other testimony that closing the gap between discovery and delivery is a major challenge in our country. Federal Government employees cannot lobby, but others do not have such a constraint and may want to consider this issue as they work with their State and Federal representatives.

JUAN YOUNG

- Mr. Young, age 67, has lived in the United States for 35 years. He had been a jockey for 20 years, until he suffered a broken leg. A year ago, he had his prostate checked and was found to have prostate cancer and a Gleason score (a measure of tumor aggressiveness) of 6 (on a scale from 2 to 10). He has been told he may live another 2 years. He has found that practicing yoga makes him feel better. He expressed concern that new medications for cancer and other diseases are so expensive that the average person cannot afford them. He asked that the Panel raise this issue with President Bush so that a way can be found for all people with cancer to get the medications that will best treat their disease.

DR. DEAN PRINCE, MOUNTAIN LAKES, NEW JERSEY

- Dr. Prince, who has stage IV colon cancer, has been using marijuana to help relieve his chemotherapy-related nausea. He has found it much more helpful and far less expensive than other drugs prescribed for him for this purpose. He has had chemotherapy for the past 10 months; his side effects were so severe that he would have to be hospitalized for 2 days of each week he was treated. This meant that for 8 days of every month, he would be unable to eat or drink and would require intravenous fluids because his nausea was so severe. His doctors were about to stop his treatment. They recommended that he try marijuana, and it has been so effective in restoring his appetite that he

has regained the 31 pounds he had lost because he was so ill. Dr. Prince noted that by buying and using marijuana he is risking his Drug Enforcement Administration license to prescribe controlled drugs and that he is at some risk buying the substance on the street, but that it is so important to his being able to tolerate chemotherapy that he is willing to take these risks. He believes it is unfortunate that politicians and the Supreme Court have prevailed in keeping the medical use of marijuana illegal. He indicated that he has a clear conscience in this regard, because he is using marijuana only for medical purposes. Dr. Prince hopes the legal ruling will be overturned in the future.

Dr. Prince also indicated his belief that people should not feel ashamed of accepting charity care or government assistance because the decisionmakers have constructed a system that makes it impossible for many people to obtain care on their own. People who are sick and need help have to learn to manipulate the system to serve them and play by the rules that have been established by others. He also indicated that the doctors he has dealt with during his illness, particularly oncologists, have been caring and giving people who willingly supply their services to a lot of needy people.

JOAN LAURETTE SAVARY, KENSINGTON, MARYLAND

- Ms. Savary is a 4-year survivor of stage IV colon cancer. She believes she has received excellent care. She recounted that her doctor asked permission to present her case to other surgeons and oncologists because he knew that many of them do not treat patients whose disease has already metastasized and do not recommend clinical trials or other care for such patients. Ms. Savary also indicated that she has been urging her husband, who is 65 years old, to get a colonoscopy, but his doctor says he is not eligible to receive one since he has no symptoms. Similarly, she wants her older daughters to be tested. The daughter who is 37 years old has been told she cannot get a colonoscopy until age 50, despite her high risk for the disease. Dr. Freeman noted that as of July 2001, Medicare will pay for colonoscopy for beneficiaries, even in the absence of symptoms. Dr. Huerta indicated that colorectal cancer is found at a curable stage in only 26 percent of people diagnosed with the disease. In many cases, the problem is lack of knowledge about the disease and its prevention and detection.

SUSIE MILLER, CHESAPEAKE, VIRGINIA

- Many patients go to the same doctor over a period of years and are treated for symptoms as individual events. There needs to be a way to pull all of this information together to see if there is a pattern or whether, in the aggregate, the symptoms point to a particular disease or condition. Such was her husband's case. Mr. Miller has carcinoid syndrome. His symptoms began in 1977, but he was not diagnosed until the mid-1990s, when an urgent care center in their area put all of his symptoms into a computer and determined that Mr. Miller needed to see a surgeon. Dr. Huerta noted that carcinoid syndrome is one of a number of conditions that can imitate many other conditions and can therefore be difficult to diagnose.

ROSA LUTÍN, WASHINGTON, DC

- Ms. Lutín thanked Dr. Huerta for the valuable information provided through his radio program and expressed her hope that more prevention programs can be established.

JOAQUIN PANIAGO, WASHINGTON, DC

- Mr. Paniago indicated that because he is uninsured, he would be unable to get preventive care were it not for Dr. Huerta's program, which he attends annually. He believes prevention is very important and that he might not have lost his mother to cancer if she had had prevention information. Dr. Huerta

indicated that the Preventorium, established 6 years ago, seeks to stimulate attitude and behavior changes by saturating the community with cancer prevention messages through 90-second daily radio spots, 1-hour talk shows, 1-hour television shows, the Internet, and articles placed in local newspapers.

JUDY LIEBERMAN, DOVER, DELAWARE

- Ms. Lieberman lost her husband to cancer. In addition, a screening mammogram that she had taken was lost for a year, and when she had a repeat mammogram, the 1-centimeter density found in the first mammogram had grown to 3.5 centimeters, necessitating a simplified radical mastectomy. Ms. Lieberman had never been notified of the radiologist's findings on the first mammogram. Dr. Freeman noted that it now a Federal requirement that radiologists provide a report directly to the patient as well as to the referring physician to help ensure that suspicious findings do not accidentally go unreported. She asked whether any central reporting system exists that might have prevented her situation. She also believes that a patient advocate program is essential to help people know what programs might be available to them and to help them through the system.

DR. KERNER

- There is a DHHS Quality of Care Committee that is evaluating quality of care across all the different diseases, but it is being led by the NCI because of concerns such as those raised by speakers at this meeting. In addition, the NCI's Center to Reduce Cancer Health Disparities is examining how quality of care varies among different population groups. It is very important that these patient and caregiver stories continue to be told and that they become part of the public record so that we can marry the science of understanding barriers to quality care with the human stories describing who suffers when care is inadequate or when quality care is lacking. It is the combination of these two things that will lead to system change.

DR. GABE

- Dr. Gabe indicated that his group has twice tried, unsuccessfully, to win contracts with the local VA hospital to provide radiation oncology services in his area. Another facility that, unlike Dr. Gabe's facilities, is not accredited has consistently been awarded these contracts. This causes patients to drive 2 to 3 hours each way to receive radiotherapy. Because of the distance, some refuse care. Some of these veterans are Medicare beneficiaries, however, and although it is often hard to reach them, Dr. Gabe's group encourages them to come for treatment. All patients are accepted, and payment plans are worked out individually, based on ability to pay for the 20 percent not paid by Medicare. Dr. Gabe suggested that quality be factored into the decision process for VA contracts rather than just the bottom-line dollar figure. Veterans who use the VA system should have the ability to go to any facility they wish as long as an agreement has been established between that provider and the Veterans Administration hospital. Veterans should not be limited to a single facility.

MS. ELNORA MARSH, MIFFLINBURG, PENNSYLVANIA

- Ms. Marsh's breast cancer went undiagnosed for 4 years. She had two tumors, only one of which she could feel. On three occasions in one year, Ms. Marsh reported her symptoms and was told by her doctor that she was just suffering from stress because her husband had had a stroke. She insisted something was wrong because she was experiencing pain. She was sent for a kidney scan, which was negative. She returned again with pain in her abdomen; a gastrointestinal series was ordered, which was also negative. Finally, Ms. Marsh refused to leave the doctor's office until she was given a mammogram. The mammography technician felt the lump that the doctor had just said was not there.

A malignancy was found, but because he was ill with the flu, her doctor simply told her the result and refused to talk with her further. A week later, the doctor was still ill; Ms. Marsh returned to the office to meet with her doctor's associate, only to be told she had an ulcer, not cancer. However, the doctor indicated that her mammogram was abnormal and should be repeated. Two tumors were detected. Ms. Marsh recalled the mammography technician asking her what she had done about "the first one" but did not at the time understand what she was talking about, and, not wanting to appear foolish, did not ask. The technician was referring to the tumor that had shown up on her mammogram 4 years earlier. She was referred to a surgeon out of town, but all her x-rays were lost in transit between her doctor's office and that of the surgeon. Ms. Marsh later learned that she was one of five of her doctor's patients to have this happen. She is grateful that mammography reports provided directly to the patient are now mandatory.

UNIDENTIFIED FEMALE SPEAKER

- The speaker lost her mother, who had cervical cancer, 2 years ago. Her mother was originally from Bolivia and had been screened regularly there—and also in the United States after moving here. When she was diagnosed with cancer, she was given the news very bluntly and was so shocked by the news that she was unable to act. The family sought a second opinion from Dr. Huerta, who fully explained the mother's condition and the treatment that was needed. Because of the caring and respectful way she was treated, this patient accepted the need for treatment. Her original doctor, though Spanish-speaking, was insensitive to the communication needs of the patient. The speaker also noted that at the hospital, her mother and other patients were treated without consideration. After surgery, she was told that no further treatment or medication was required. Her cancer recurred in a year. She was told she needed additional surgery and chemotherapy. However, all of the information provided was in English, and the doctor no longer saw her personally but sent an assistant. The speaker's mother was so despondent that she became suicidal. She was extremely sensitive to the chemotherapy and took only three sessions before stopping treatment. According to her wish, her daughter cared for her at home until her death. The speaker noted how difficult this experience was for the whole family and wondered why her mother's cancer was not detected earlier.

BRENDA BILLINGSLEY, WILMINGTON, DELAWARE

- Ms. Billingsley believes money is the underlying reason patients' cancers are missed. The insurance companies and HMOs want to make money and, it is believed, penalize doctors if they perform extra tests. In her own case, Ms. Billingsley's cancer went undetected because her insurance company would not pay for a colonoscopy.

DR. FREEMAN

- Dr. Freeman thanked Dr. Huerta for moderating the evening's session and noted the testament made by the presence of so many members of the local Hispanic community to his warmth and positive force in the community.

MAY 25, 2001

OPENING REMARKS, DAY 2—DR. HAROLD FREEMAN

In opening the meeting, Dr. Freeman reiterated the impetus for the seven regional meetings and underscored the Panel's interest in hearing from people throughout the country and the problems they have experienced in accessing cancer information and cancer care.

MULTISTATE ISSUES PANEL

Presenters

Ms. Nancy Davenport-Ennis

Ms. Kathleen M. Dietsch

Ms. Rani Haigler

Ms. Jackie Bong-Wright

Ms. Ellen L. Stovall

MS. NANCY DAVENPORT-ENNIS

Background

Ms. Davenport-Ennis is Founding Executive Director of the Patient Advocate Foundation, which serves cancer patients in need across the Nation. Since the Foundation's inception 4 years ago, 8,074 cases have been handled to closure.

Most of the patients who have contacted the Foundation for help have been adult females (76 percent of cases), with 22 percent adult males. In terms of ethnicity, 75 percent have been Caucasian, 13 percent African-American, 6 percent Hispanic, and 1 percent Asian. These figures suggest the need for outreach programs involving other organizations. Most callers have been 46 to 55 years of age, followed by those aged 56 to 65 and those 36 to 45. Though the Foundation has provided assistance to patients with 278 different types of cancer, "female" cancer cases number four times as many as any other cancer type.

Sixty percent of callers contacting the Foundation for help have been insured. Of those, 26 percent were members of ERISA plans. Sixteen percent of callers were uninsured; 4 percent have been on Medicaid; and 9 percent have been Medicare beneficiaries. The principal problems of the uninsured population were: first, debt-related issues; second, how to access the system; and, third, denial of services. Among the Medicaid population, 34 percent of callers were confronting denial of services. Forty-one percent of Medicare patients were confronting denial of services. Among those with insurance, 42 percent were confronting specific denial of services.

Denials are most common in coverage for early detection and prevention services (52 percent of callers)—many of these patients had preexisting conditions—and denial of prescription drug benefits (32 percent of callers). Insured patients, regardless of their income level, insurance status, or location, often do not receive the most advanced treatment for their particular diagnoses.

Key Points

- Ms. Davenport-Ennis recounted the case of a 10-month-old girl in Tennessee who was diagnosed with kidney cancer. This patient's intense treatment was being rendered by the children's hospital approximately 45 minutes away from the small town in which the family lived. The patient was expected to need at least 12 more months of treatment. The patient's mother was single and had two

other young children and unreliable transportation; she was trying to maintain at least part-time employment at a retail store while caring for her seriously ill child. The baby's illness had placed severe financial strain on the family due to the mother's loss of work. The patient's mother desperately needed food assistance, subsidized housing closer to the hospital, childcare help, and some form of monthly income subsidy. The mother had contacted the county Department of Human Services (DHS) on several occasions to request help but was told that regardless of her circumstances, she must come to the DHS office, apply, and wait several weeks for a response. She had also applied for public housing in her city but had gotten no response there, either. The obstacles this parent confronted in trying to get necessary cancer care for her daughter were: unreliable transportation, lack of adequate childcare for other children at home, lack of compassion from an overburdened hospital and agency caseworkers, and institutional unwillingness to make exceptions regardless of need or to offer compassionate processes for her situation.

- Insured patients may have access to specialty care blocked by their health plans due to the location of the physician or facility. For example, a 20-year-old insured female patient living in North Carolina was diagnosed with acute myelogenous leukemia. Her health began to fail, and her physician sought to have her admitted to the University of North Carolina (UNC), which was an approved provider. No bed was available, so she was admitted to the Duke University Medical Center. The patient completed two rounds of chemotherapy and was then notified that she must move to the UNC facility, or she would have three options: She could remain at Duke and continue to receive care but be subject to a deductible of 50 percent of the total charges; she could be transferred to UNC and have the regular plan benefits; or she could change the insurance plan she had to a Preferred Provider Option (PPO) plan, which would have resulted in a deductible of \$250 per day. The patient was not able to afford that, and the Foundation was able to negotiate an exception that allowed her to stay at the Duke University Medical Center.
- Insured patients also face denials for prescribed treatments or diagnostic tests due to plan language and benefit restrictions. In one such case, a 50-year-old male insured patient living in California had a family history of colon cancer: His father, grandfather, uncle, and two brothers had all been diagnosed with colon cancer by age 50. Therefore, his physician recommended that he have a colonoscopy when he turned 50. That screening was denied by the insurance company based on the fact that he did not at that time have a specific medical diagnosis.
- Uninsured patients often do not qualify for Medicaid or charity care programs due to their income level, their marital status, their lack of minor children, or their early stage of illness, as is illustrated by a 39-year-old female uninsured patient in New Hampshire diagnosed with thyroid cancer. Her husband was employed and earned \$2,000 per month. She was then unemployed, but her doctor felt that with care, she could go back to work in a few months. She had a 19-year-old son living at home and going to college full-time. However, in New Hampshire, to qualify for Medicaid she had to meet two criteria: She had to provide the State with documentation from her physician that she was permanently and totally disabled, and she had to have a dependent child living in the home if she was under the age of 65 and needing this assistance.
- Uninsured patients are typically restricted to care that can be rendered within their State of residence, so access to clinical trials or specialized care for rare cancers is severely limited for Medicaid patients located in certain geographic areas. These patients also face limited treatment capabilities, outdated equipment and testing procedures, and physicians with no direct experience in orchestrating care for their particular illnesses. For example, a 4-year-old girl in the Medicaid program in Florida was diagnosed with a very rare brain tumor. The particular type of physician she needed was a pediatric neuro-oncologist. There was no physician in Florida with those credentials. The child was denied referral to Duke University Medical Center, where that expertise was available.

- Uninsured Medicaid applicants must contend with widely varied State guidelines. In some cases, State of residence can severely compromise a patient's access to appropriate cancer care. Consumers are often counseled that there are too many criteria to publish and that applications are handled on a case-by-case basis. The average length of time for a Medicaid application to be reviewed is 90 days; for many patients, that is far too long. Many States require that an applicant be approved for Social Security Disability Insurance (SSDI) as a prerequisite to receiving Medicaid benefits, yet when they are approved for the SSDI benefits, their income then exceeds the level that would allow them to qualify for Medicaid.

Recommendations

- Develop a national program to address the needs of the uninsured. Specifically: (1) reform the current Medicaid program to include income guidelines that allow two-wage middle-class families confronting the loss of one income due to a cancer diagnosis to qualify for tiered benefits that conform to their needs; and (2) study and review the current criteria for qualifying for Medicaid and Social Security Disability to resolve conflicts.
- Launch a national public information program to educate Americans about the reality of health care access in this country.
- Analyze State risk pool information and inform the public of the benefits and failures of State risk pools. Help consumers understand that the cost of care through a State risk pool is usually prohibitive and that the criteria to procure coverage through the risk pools are strenuous and preclude the majority of applicants from approval. In addition, many State risk pools are closed and not accepting new enrollees.
- Evaluate the State CHIPs (11 States still do not offer this coverage) and accelerate dissemination of public information about enrollment.
- Inform Americans about universal programs that offer assistance to the un- and underinsured, such as managed prescription plans and church and ecumenical council programs.
- Expand person-to-person counseling services by Medicaid, Medicare, and Social Security, and offer flexible hours so consumers can reach them at times other than Monday through Friday, 8:00 a.m. to 5:00 p.m.
- Expand public information campaigns informing Americans of the specific features, benefits, and limitations of Medicare, Medicaid, and Social Security programs. Challenge public service organizations, the media, medical providers, patient advocacy organizations, and Federal and State agencies to collaboratively develop materials that are easily understood and programs that offer options for information delivery (e.g., seminar format, online information).

MS. KATHLEEN M. DIETSCH

Background

Founded 12 years ago, Hospice Caring, Inc., is a nonprofit, nonmedical hospice in Montgomery County, Maryland. It served 479 patients and their family members in 2000. These patients were served by volunteers who, together, contributed 22,000 hours of their time.

Key Points

- Care does not end once it is determined that aggressive treatment will not produce a cure. Hospice philosophy focuses on the continuation of care.

- Many patients still do not know that hospice care is an option. Many doctors are not giving patients the information they need to make choices about care at the end of life. Part of the problem comes from the personal influence of primary care physicians. Physicians are people, too, and they have their own thoughts about death. A number of recent national surveys indicate that the longer a physician has a patient, the more difficult it is to tell that patient that his or her time is limited. While this is understandable, it does not help the patient.
- Medical school education on death and dying is extremely limited—not so much about physiological death, but about a person’s life while he or she is dying. People do a lot of living as they are dying; most do not die suddenly in auto crashes and the like. Dying occurs in increments. Physicians need a different type of, amount of, and approach to their education about dying in order to help their patients.
- Pain management must be better addressed by the medical field. Pain very often is not controlled as one is dying, and many people die in significant pain. We also need to take up this issue with our legislators; if we do not, we may find ourselves sitting beside our dying spouse, mother, father, or child, and the pain will prove just as unbearable for us watching.
- The underserved among those with end-of-life care needs include the elderly, those born in other countries; and those who live alone. When a person is ill with cancer—or any disease—he or she does not have the energy to pound on the door or make the tenth phone call to say, “I want; I need.” Many people who live alone do not get the care they need because there is no one there to help them.
- People are also under the impression that only older people go to hospice. Hospice Caring is currently serving two small children. However, the elderly in the 75- to 80-year range come from a generation for which it was considered inappropriate to ask the doctor questions or demand better care. If these patients are to receive the care they need, somebody has to advocate for them, because they are unlikely to do it themselves. Innumerable times, Hospice Caring has worked with elderly patients who said of their doctors: “Well, he thought he was helping me,” and did not know they had the right to say, “Just a minute, what you did for me isn’t working.” These are the reasons so many people are underserved.
- Nationally recognized associations for specific diseases exist and are financially secure beyond belief; they need to do more to help patients. Scientifically, we have the best possible care, but it does a patient no good if he or she does not know about it or cannot get to doctor’s appointments. Communities should approach the local chapters of these organizations and encourage them to do more than provide glossy brochures.
- Only about 200 hospice models like Hospice Caring exist within the United States. These hospice models reflect the communities in which they are located. What works in one place may not work elsewhere. The programs must be tailored to local needs.
- Hospice Caring does not accept any government money in order to avoid the restrictions on care that governmental funders impose. Instead, the program is run by volunteers, and overhead is covered by donations. This hospice model also works because it offers people in the community a way to be useful that they might not have considered.
- By not accepting Medicare funds, for example, services are not limited to 6 months’ duration. When people are dying, they do not do it on schedule. Many people defy their prognosis. The hospice is now serving a young woman of 41 who has four young children. She has been in three medical hospices and been told four different times that she had 6 months to live. She is still alive; she has four boys to raise.
- Hospice Caring can serve the people who often fall through the cracks—the uninsured—because services are free.

- The nonmedical hospice also has a role in advocating for the patient. In a medical hospice, one cannot continue with aggressive treatment. This rule works for a lot of people, but not for all. A person should be allowed to continue treatment and still receive hospice services if he or she so wishes.
- The nonmedical hospice can begin working with patients while they are still taking aggressive treatment and follow them through to the end, helping them to die the way they want. It is a complete plan of care that does not stop when the doctor feels that chemotherapy is not going to work.

MS. RANI HAIGLER

Background

Ms. Haigler is a Patient Navigator and Outreach Specialist with the George Washington University Medical Center's Mobile Mammography Program and Breast Care Center. The Program, initiated in 1996, provides screening services to insured and uninsured women in the metropolitan area of the District of Columbia, Maryland, and Virginia.

To date, the Program has screened about 10,000 women; of these, half have been underserved or uninsured.

Key Points

- It is the job of the Patient Navigator to work with any uninsured patient who has an abnormal mammogram to help her get the services she needs. To date, six uninsured women have been found through the screening program to have cancer. In each case, it has been necessary to work with the system in a very different way to assist each woman successfully. Because this program works in all three jurisdictions (Maryland, District of Columbia, and Virginia), it is responsible for making sure that women secure services and meet the criteria in the jurisdiction in which they live. This information can be difficult for the patient herself to obtain, particularly under the stress of a possible cancer diagnosis. The Program works with the Breast and Cervical Cancer Early Detection Programs (BCCEDPs) that exist in all jurisdictions. However, they are operated differently in each jurisdiction. Most of the women seen by the Program are residents of the District of Columbia, and the Program is a direct provider for the DC BCCEDP, called Project WISH. This relationship somewhat simplifies working through diagnoses with women who have an abnormal mammogram.
- Until October 2000, there were no treatment services available for women diagnosed with breast cancer. It was the Navigator's job to try to make sure these women were treated. Fortunately, the Program's parent organization, the George Washington University Medical Center, provides treatment for anyone diagnosed through the Mobile Program if no other source of care is available. The Breast and Cervical Cancer Treatment Act was passed for women 40 years of age and older enrolled in the BCCEDP to allow any woman diagnosed through the Program to be enrolled in Medicaid for the duration of her treatment. Prior to the Act, these women were not eligible for Medicaid if they had no young children or if they worked and had an income that exceeded the Medicaid ceiling. Unfortunately, women aged 35 to 39 who may need screening are not eligible for this benefit.
- Maryland and Virginia each have different criteria for eligibility under the Program. Maryland has an excellent program in which a fund for treatment costs has been established specifically for any woman who has been diagnosed with cervical or breast cancer, regardless of whether she is enrolled in the BCCEDP. This fund is a safety net to ensure that treatment is available to any woman with breast or cervical cancer.

- Virginia’s program has seen numerous changes over the years, and they have not necessarily been changes for the better. While Virginia has a BCCEDP, it is run regionally, and each region runs it differently. The Northern Virginia region has cut back its level of services in the past year, leaving many women aged 40 and older in need of services and unable to receive funds from the Federal program. In addition, some of these women may be found to have an abnormal mammogram (because they are screened using grant funds) but may not be enrolled into the Virginia Breast and Cervical Cancer Program; as a result, if they are diagnosed, they are unlikely to be treated through Medicaid or State funds.
- In addition, age of eligibility varies among the jurisdictions. In the District of Columbia, women are treated starting at age 40; in Virginia, women are treated starting at age 50. Considering that the NCI and ACS guidelines recommend annual screening for women 40 and older, the gap in Virginia is problematic, since the program follows the ACS screening guidelines.
- Thus, lack of consistency between jurisdictions has been a major issue for women living in the Washington metropolitan area. Simply by crossing the street or crossing jurisdictional lines, a woman will receive different services. It has been Ms. Haigler’s responsibility to keep up with changes in each jurisdiction’s program and try to make sure that women are being treated in whatever way possible. These inconsistencies should be addressed, since the Program is federally funded.
- More education and outreach into the communities is needed to help educate women about screening and outreach programs such as the BCCEDPs. Many women do not know that these programs exist.

MS. JACKIE BONG-WRIGHT

Background

Ms. Bong-Wright is President and CEO of the National Foundation for Vietnamese American Voters, Inc.

Incidence rates of cervical cancer among Asian-American women in the United States show small but significant increases. Cervical cancer rates per 100,000 women by ethnicity from 1988 to 1992 show that Vietnamese women have 43 cases per 100,000 women—three times higher than the next highest group, Latinas, at 17.1 per 100,000. Rates for other groups are: Korean women, 15.2 cases per 100,000; African-American women, 13.2 cases; Caucasian women, 7.5; and Japanese women—the lowest—5.8 cases per 100,000 women.

In 2000, the Virginia BCCEDP screened 3,473 women whose racial breakdown was: 1,946 white; 1,295 African-American; 105 Asians/Pacific Islander; and 127 “Other.” Of these, 21 women were diagnosed with breast cancer: 11 white, 8 black, 1 Asian, and 1 woman with no race specified. Seven women were diagnosed with cervical cancer: five white and two black.

Key Points

- Barriers to health care among Asian-American women include a low rate of cervical cancer screening. There is a lack of knowledge in this population about cervical cancer. According to NCI statistics for 1999, three-fourths of Vietnamese women do not know the function of Pap smears. Newly arrived refugee or immigrant Asian families are also placed at a disadvantage by limited English proficiency and low socioeconomic status. Adults work two or three jobs and have no time for, nor do they understand, the health system in the United States. They do not get annual checkups and are underserved and often uninsured. In addition, their acculturation to American society is slow.
- Most Asians have a different concept of wellness, which centers on happiness and health. It is a complete state of physical, mental, and social well-being. There is a unity of mind, body, and spirit,

as well as a holistic state of unity of man, nature, and the supernatural. Thus, the wellness concept is that to be healthy is to gain a balance and harmony with self and the universe, involving the concepts of *yin* and *yang*, hot and cold, and the inside and outside worlds.

- For most Asians, the concept of sickness means a disorder of two opposite life forces—i.e., imbalance between the *yin* and *yang*, cold and hot, and the inside (i.e., inside the body, inside the mind) and outside worlds. Therefore, for Asians, serious sickness also has a religious connotation that says the sick person is possessed by spirits, or (among Buddhists who believe in reincarnation) being punished for the sins of past lives. The *person* must be treated, not just the disease.
- Many Asians think that Western medicine is too “hot” (powerful) for them. Sometimes, when they are given medicine, there is a risk of overdosage or underdosage because they do not want to take the medication as prescribed. These patients may choose to take no medication, using instead herbal or alternative medicines. Many also fear surgery because they believe that the soul is attached to the parts of the body; if you remove the cause of the illness, it will cause death.
- There is also fear and embarrassment during gynecologic examinations, particularly among Asian women. Most do not want to go to male gynecologists, but even with women gynecologists, many women feel embarrassed about the examination and about asking questions.
- Vietnamese women gynecologists have indicated that when they find cancer in Vietnamese women, these patients often do not trust them and think that the *doctors* have something wrong, not them. They also resist accepting a diagnosis because they think that only “bad” women (i.e., those not from good families, who are promiscuous, or who have had more than one husband) develop cervical cancer. Mechanisms are needed to reach out to and educate Asian women; these should include the media, conferences, videos, and information and referral centers. In addition, support groups are needed. Many Asian patients also need transportation assistance to get to doctor and hospital appointments.
- American health providers are unfamiliar with Asian-American cultures. We need to have community networking, cross-cultural training for health providers, and direct funding of community-based organizations. About 36 Vietnamese organizations exist in the Washington, DC, area, but they need to connect and form a bridge between the health centers and the community.

MS. ELLEN L. STOVALL

Background

Ms. Stovall is President and CEO of the National Coalition for Cancer Survivorship (NCCS) in Silver Spring, Maryland. Diagnosed with cancer in 1971, at age 24, she began her treatment on the day President Richard Nixon signed the National Cancer Act, which launched the War on Cancer.

Ms. Stovall noted that she was diagnosed with cancer under the very best of circumstances: She had access to health care and had no cultural, geographic, transportation, economic, social, stigmatic, or informational barriers. Although she was unable to participate in a clinical trial, she was treated at a major urban cancer center. Yet, even under these optimal conditions, she has lived with the knowledge that she could have been spared treatment-related infertility had she been treated at a center using newer radiation equipment.

Key Points

- In 1971, we had no national insurance coverage for clinical trials in the private sector, and we still do not. Coverage is determined on a State-by-State basis. It took the last 8 years to secure national

coverage of cancer clinical trials for Medicare beneficiaries; that battle should not have taken nearly so long to win.

- A 1999 report by the Institute of Medicine at the National Academy of Sciences states: “There is no national cancer care program or system of care in the United States. The National Cancer Policy Board has concluded that for many Americans with cancer, there is a wide gulf between what could be construed as the ideal and the reality of their experience with cancer care.” This groundbreaking report does not say that *no* progress has been made in 28 years; scientifically, we have made tremendous progress, and 10 million people in this country today can identify themselves as cancer survivors and patients because of progress in cancer care.
- However, our health care system and our societal attitudes lag far behind our scientific advances. Reports, testimony, expert panels, and articles in the popular and medical literatures continue to state the same grim statistics: that we are the only industrialized nation without universal access to health care; that we have more than 44 million uninsured people and an equal number of underinsured, most of them employed. Good care at the end of life is increasingly unaffordable and unapproachable. These statistics are compounded and made ironic by the news of scientific advances. For example, recent news has been filled with articles about a new treatment for chronic myelogenous leukemia called STI-571, or Gleevec. However, because this new drug is administered orally, it is not reimbursable under the Medicare program. Though this realization was astonishing to members of the National Cancer Advisory Board, a presidentially appointed advisory body to the NCI, such a disconnect between science and the health care system and its reimbursement policies is familiar to advocates. Similarly, many women need to take tamoxifen to control breast cancer, but it, too, is administered orally and is not reimbursed under Medicare or by many private insurance plans. We know very well how to manage the distressing symptoms of cancer (e.g., pain, nausea, fatigue, lack of appetite, depression), yet for most, the suffering often goes unrelieved. The American public needs to be more aware of these problems. We desperately need to realign our health care system to accommodate caring for people with cancer.
- A key question is: How much evidence concerning the problems of the health care system and their effects on people with cancer is enough? Reports containing hard, quantitative data have been prepared by the Institute of Medicine, the Robert Wood Johnson Foundation, the California Health Care Foundation, the Pew Charitable Trust, the Commonwealth Foundation, and numerous other organizations. In addition, the cancer community has addressed this issue many times at the request of Congress. For example, in 1991, Congress asked the National Cancer Advisory Board, upon the 20th anniversary of the National Cancer Act, to provide a report on the measures of progress against cancer. This report, though excellent, was produced at a cost of hundreds of thousands of tax dollars, yet it said the same thing as many of the reports that preceded it.
- Another report to Congress about cancer, *Cancer at a Crossroads*, concluded that all health care reform proposals before Congress at that time would be devastating to the War on Cancer. The health care system remains out of control. Worse, it continues to unravel despite an ever-changing patchwork of laws, organizations, and financing plans designed to increase access for at least some groups—and despite the best economic times the country has known for decades. Employer-based insurance is shrinking; coverage for poor children is lagging; and the managed care revolution is widely seen as being at least as pernicious as it is beneficial. Clearly, the situation will deteriorate further when an inevitable recession occurs.
- An article written by Drs. Frank Davidoff and Robert Reinecke of the Jefferson Medical College—published in the *Annals of Internal Medicine* last April—notes: “Looking ahead, there is a special irony that we may never realize the enormous potential benefits of the Human Genome Project because persons found to be at increased genetic risk are likely to be excluded from health care coverage.”

- Our inability to make a better, if not a perfect, system does not result from lack of trying. Unfortunately, our deep distrust of central government control coupled with our profound faith in the moral precepts of commerce and the market, our driving need for personal autonomy, and our occasional spasms of intense partisanship have frustrated our best efforts at system improvement.
- Most Americans are intensely aware of the hazards of exclusion from the health care system and, at some level, value the principle of social justice that underlies equity, if not equality, in access. But that principle has, somehow, never found enduring public expression. The time has come for the cancer community—as defined by all of the courageous people represented by those who have testified before the Panel over many years—to find enduring public expression and raise their voices on behalf of quality cancer care for all Americans.

Recommendations

- In its report, the President’s Cancer Panel should make clear to the President that we have sufficient evidence of the problems in the health care system and their impact on people with cancer. Rather than more studies, we need advocacy, action, and accessibility.

MULTI-STATE ISSUES PANEL—DISCUSSION

Key Points

- Some have called for a 28th amendment to the Constitution. Though not politically feasible, something that provocative may need to be proposed to again stimulate serious consideration of health care reform. Following the failure of the Clinton administration’s attempt at health reform, we have achieved only small and incremental elements of reform. We have yet to pass a Patients’ Bill of Rights.
- The qualitative and quantitative body of evidence that currently exists should be married to the science, and a plan should be developed to provide for either hearings or open Congressional exploration of what has already been found. Without such visibility, the Panel’s report will fall on deaf ears, as have many previous reports.
- As part of their medical education, doctors need to more thoroughly understand the dying process and care options. In addition, they need to be aware of their own feelings about death and dying so that they do not interfere with patients when it is time for them to consider dying and their wishes for care at the end of life. In addition, the rules and regulations that govern hospice care need to be revised. Currently, nonmedical hospices in Maryland have to comply with the same standards as medical hospices, even though their services are quite different.
- The Panel has heard almost uniform support for universal access to health care in America, or at least a minimum level of care—including care for cancer. However, universal access would not mean access to anything a patient might want or a physician might recommend if it is not evidence-based. These will be difficult decisions. If we truly had a system in place that could manage a process of well-vetted guidelines (i.e., some minimally acceptable standards of care that everyone used), it would be a beginning. But the politics of the medical community will likely prevent this from ever happening. However, failing such an action, the access issue will be almost meaningless.
- Ms. Haigler reiterated that in the time she has been with her program, 6 cases of invasive cancer have been found in approximately 10,000 screened women. Her caseload of women with abnormal mammograms averages 20 per week but varies depending on the sites the mobile unit visits and the proportion of uninsured women who live there. Despite these variations, every woman with an abnormal finding is followed up.

REMARKS

HON. TOMMY G. THOMPSON

SECRETARY, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (DHHS)

Key Points

- Secretary Thompson underscored the importance of the meeting and thanked Dr. Freeman, Dr. Kirschstein, and all the participants for their efforts. Cancer is an insidious disease that must be overcome, and we are making a lot of progress against the disease. As someone who has lost a grandfather, a mother, and a mother-in-law to cancer, and as the spouse of a woman with breast cancer, Secretary Thompson noted, he is well aware of the devastating impact cancer can have on an individual and a family.
- The testimony of the participants and the insights gained from them are valuable input for the DHHS. The Department is a full partner in the battle against cancer. No one organization or person can do the job alone, but together we form a powerful alliance against a common enemy.
- Secretary Thompson noted that coming from a small town in rural Wisconsin has given him a perspective that he has carried with him to his work: first as Governor of Wisconsin, and now to his position as Secretary of DHHS. People in small cities or towns are not statistics or numbers on a page—they are real individuals. When someone gets a disease like cancer, it affects the whole community because everyone knows that person as a friend, a neighbor, and a loved one. Public policies affect real people, not nameless lines on an actuarial table.
- In his wife Sue Ann's fight against breast cancer, Secretary Thompson has learned about the fear of hearing that a loved one has cancer, the courage it takes to fight the disease, and the joy of seeing someone win that fight. Such victories would not be possible without the help of the dedicated physicians, nurses, and researchers who work to thwart cancer. Though we each have our own unique story, we share a common basis—the need to win the fight against cancer.
- The stakes are high—both for us personally and for our country. Every year, 1.2 million Americans develop some form of cancer. One of every four deaths that occur annually is cancer-related. That equals 550,000 individuals who have loved ones and survivors. But there is good news. Astonishing new treatment possibilities are on the horizon, such as treating cancer at the genetic level and eliminating diseased cells while protecting healthy ones. The recent news about Gleevec and its possibilities is one such example. Its development marks one of the rare moments when we can legitimately say that it appears that we have beaten back a vicious form of cancer. Gleevec is the first cancer drug that is a product of molecular targeting, the groundbreaking ability to deliver a drug directly to diseased cells while leaving healthy cells alone. Gleevec targets a single cancer-causing protein and turns off its signal to produce leukemia cells. We have not had the drug long enough to know if its effects are permanent, but the early research is promising.
- We have the best doctors, researchers, and scientists in the world working for us at NIH and the in Department. Dr. Richard Klausner has been a fine steward of the NCI and is a valued member, partner, and friend of the DHHS team.
- The network of Cancer Centers conducts extensive human clinical trials of new treatments and also keeps local doctors and other health care professionals abreast of the latest developments. NCI has supported 71 clinical trials of new drugs. Gleevec is the first of these new treatments; others are in the pipeline and will soon be ready to come onto the market. Data from these trials are being reviewed, and this line of research will continue to be explored. Another avenue of research is in antiangiogenesis—methods of denying malignant tumors the blood they need to continue to grow.

- The NIH operates an unrivaled cancer surveillance and epidemiology program to monitor cancer at every level.
- President Bush has submitted an aggressive, forward-looking budget designed to boost anticancer efforts as never before. The President is sending a clear message. He does not want us just *treating* disease, he wants us *beating* disease, especially such an onerous disease as cancer. The President's budget reflects his seriousness about the administration waging a fight to win the war against cancer. The 2002 budget provides \$23 billion for the NIH, a \$2.75 billion increase over 2001. This is the largest increase ever for NIH, and it may be increased even further by Congress. It includes funding for 34,000 NIH research grants, the most ever provided. Many people do not realize that 75 to 80 percent of the dollars that go into NIH go back as grants to cancer clinics and other research centers all over America. A cornerstone of this year's NIH budget is an increase of \$514 million for cancer-related research in 2002—a 12 percent increase.
- In addition, NIH is revitalizing the way it develops and conducts clinical trials of cancer treatments to make the trial process more flexible and more inclusive. The new system is designed to speed new ideas from the laboratory to the clinic, streamline the paperwork, and expedite the reporting process. The bottom line is that the new clinical trials system will enable people with cancer to receive a higher quality of care and receive it faster. Greater feedback is encouraged from patients and their families as well as from the researchers and practitioners who conduct these trials.
- The budget also includes funds to continue revitalizing key facilities at the CDC in Atlanta.
- CDC's cancer screening program is available to poor women nationwide. Under legislation that took effect last October, the Federal share of costs for treating cancer in women on Medicaid can now go as high as 85 percent; this change will enable many disadvantaged, poor, and minority women to receive treatment they could not otherwise afford.
- On a broader level, the President's budget seeks to improve access to basic health care for everyone—including those with limited incomes and limited access to care—so that diseases such as cancer can be diagnosed and treated as early as possible. The administration is also mindful of the 43 million people in this country who lack health insurance and is looking at ways to address that problem.
- The administration will also be looking at ways to reform the National Health Service Corps to better target placement of providers in areas experiencing the greatest shortages of health professionals.
- These are significant and attainable goals that will help deliver quality care to people in some of our neediest communities.
- The President is committed to strengthening and modernizing Medicare—in part by adding a prescription drug benefit. Last September, Medicare began paying for the routine health care costs of beneficiaries in clinical trials.
- The proposed budget goes beyond numbers and programs. It is about innovation, effectiveness, and even moral courage. We can no longer be content with doing things as they have always been done. We need to persevere until the threat of cancer is much more distant and much less severe. With the help of people such as those in attendance at this meeting, that is exactly what the President, the Secretary, and DHHS plan to do.

DISCUSSION—SECRETARY THOMPSON

Key Points

- There is no question that the health delivery system in America needs some shoring up, replacements, and improvements, as well as considerable modifications. Currently, 43 million people are uninsured, and many millions more are underinsured. The administration wants to try to expand so that the underinsured and uninsured in both urban and rural areas are able to get adequate care. For this reason, an additional \$124 million is proposed to expand the number of Community Health Centers (CHCs) from 3,200 to 4,400 over the next 5 years. Currently, CHCs are the source of medical care for 11 million people. The CHCs provide good care and are doing a wonderful job. The proposed addition of new Centers should increase the number of people served by CHCs to 20 million.
- The administration also supports a tax credit of \$1,000 for individuals, \$2,000 for couples, to help them buy private health insurance. Some people criticize this approach, saying it is insufficient. However, it is a step in the right direction.
- While Governor of Wisconsin, Secretary Thompson expanded the S-CHIP (federally funded child health insurance) program for the working poor and enabled low-income families to buy into the State's Medicaid program. Currently, 93 percent of Wisconsin citizens are insured. He wants to replicate this success elsewhere in the country.
- It has now become clear that significant differences exist between women and men, and the appropriate research has not been done. Similarly, there are differences in how some illnesses impact different races, and we have not been sufficiently attuned to or cognizant of these issues. It is necessary to try to do a better job in these respects, and the NIH, CDC, and the DHHS are trying to do so.
- The goals stated by the Secretary are shared by the President and have been well received by both political parties on Capitol Hill.
- We need to find ways to persuade more people to go into the health care field. We have a huge problem quickly coming to the forefront in America: a shortage of nurses and nurses' aides, pharmacists, clinicians, and laboratory technicians. It is maintained by some that people are not choosing health-related professions because of the paperwork involved in health care. The Department is considering how this paperwork could be streamlined so that it is not a barrier.
- The Institute of Medicine recently issued a report saying that the health care system in this country is broken. It cannot be tampered with; it is absolutely broken. Within this larger issue, however, there are specific issues that are important to the cancer community. For example, Medicare does not cover oral drugs, including Gleevec and tamoxifen. The Congress and Administration are now working on an amendment to Medicare that would cover prescription medications, but it is unclear what the exact form of that benefit will be. The administration is also cognizant of the need for a basic restructuring of the health care system. This will be difficult—perhaps more so than previously—given the recent change in partisan control of the Senate. Nonetheless, great hope and opportunities for change still exist. Ms. Visco asked that the patient community be included in developing plans to restructure the health care system. The Secretary indicated that the Department welcomes this input.
- Vietnamese-American women have the highest cervical cancer incidence rate in the country. Additional funding to ethnic community-based organizations would enable those with the necessary language skills and the cultural sensitivity to reach the grassroots Vietnamese community and bring them to health units to be treated. Secretary Thompson acknowledged the need for better outreach to all communities.

STATE OF PENNSYLVANIA

Presenters

Dr. Robert S. Zimmerman

Ms. Lora M. Rhodes

Dr. Deborah Watkins Bruner

Ms. Elnora R. Marsh

Mr. Albert Calloway

Ms. Vicki Burks

DR. ROBERT S. ZIMMERMAN

Background

Pennsylvania is no stranger to the ravages of cancer. According to recent data, more than 71,000 new cancer cases are diagnosed among Pennsylvania residents each year, with almost 30,000 deaths from the disease annually. The most common new cancers are those of the breast, trachea, lungs, colon, and prostate. African-American men had the highest age-adjusted incidence rate in the State, with 647 cases per 100,000; white women had the lowest rate, at 372 per 100,000. Reported cancer incidence has increased in Pennsylvania, which to some extent can be attributed to its aging population, increased early detection, and improved awareness of symptoms and signs. Overall mortality rates show declining trends since 1993, with a drop of almost 10 percent between 1987 and 1998.

Key Points

- It is estimated that over half of all cancer patients now survive at least 5 years after diagnosis; these odds can be improved significantly through increased cancer detection, diagnosis, and treatment. This is a goal Pennsylvania is striving to reach by translating research knowledge into effective practice.
- Governor Tom Ridge has established a health investment plan that dedicates every penny of Pennsylvania's share of the Tobacco Master Settlement Agreement (MSA), totaling approximately \$400 million a year, to improving the health of all Pennsylvanians. The General Assembly has embraced this plan and is working with the administration to put the final touches on legislation to implement that plan. As part of the plan, the Governor wants to make a one-time \$100 million investment to create three life sciences "greenhouses" to enhance, share, and target Pennsylvania's rich health research and biotechnology assets to develop new health technologies and products and get them into use more quickly. This approach will attract and encourage academicians, researchers, and the business sector to identify market niches and develop commercially useful patents and applications. By attracting both prominent scientists and venture capital investments, Pennsylvania will be in the forefront of implementing the commercial development of new research discoveries, helping to narrow the gap between scientific research and its application.
- The Governor's plan will annually allocate an additional 10 percent or more of the MSA funds for broad-based health research to support biomedical, clinical, behavioral, and health services research. Health services research is particularly important; it is essential that we improve our ability to put what we already know into practice at every level.
- Pennsylvania has five NCI-designated Cancer Centers, three of which are Comprehensive Cancer Centers. These and other cancer centers have more than 160 affiliations with hospitals and physician groups throughout the State. These centers and other facilities and practices need to be linked to improve the reach of clinical trials throughout the State, and some of the research monies should be used to cover costs associated with participating in clinical trials. In addition, funds should be used to

share and develop bioinformatic capabilities to enable all the centers to communicate with each other effectively. Likewise, statewide tissue banking and other strategies can be used to identify problems, improve collaboration, and transfer best practices to all areas of the State.

- An additional 5 percent of the settlement funds will be allocated to medical venture capital, and up to 15 percent of the MSA funds (as much as \$60 million annually) will be spent on comprehensive statewide and community-based tobacco use prevention and cessation programs that follow CDC's best practices. At least 40 percent of the MSA funds will be devoted to developing low-cost adult health insurance programs along the lines of the Pennsylvania CHIP program.
- A second State initiative involves a series of roundtable discussions held with researchers from Pennsylvania's leading cancer research and academic medical centers and the Appalachian Cancer Network. The input from these discussions is aiding the Health Department and State Cancer Advisory Board in developing a strategic plan for cancer research as part of Pennsylvania's cancer control plan. The group focused on three areas: prevention, early detection, and postdiagnosis care. In addition, the group addressed several issues related to basic research and the use of cancer registry data. Among the questions addressed by the group were:
 - How many people diagnosed with cancer have ever been screened, and are we screening younger family members of people diagnosed with cancer?
 - What are the unmet needs of cancer patients and caregivers, including pain management and end-of-life care?
 - Do race, age, gender, and region affect options and outcomes?
 - What are the barriers to participating in clinical trials?
 - Is there an association between agriculture, which makes up a large segment of Pennsylvania's industry, and non-Hodgkin's lymphoma?
 - How much liver cancer is related to hepatitis B and C?
- When key differences and gaps are identified, the State's cancer centers, public health entities, and volunteer health organizations will work at the community level to take action to bridge those gaps. Doing so may require initiatives in clinical medicine, education, access, and other areas.
- The National Dialogue on Cancer (NDC) is a consortium of organizations and officials across the country dedicated to eradicating cancer as a major public health problem and improving the quality of life of cancer survivors. The NDC is co-chaired by former President George Bush and former First Lady Barbara Bush. Governor Tom Ridge chairs the NDC's Comprehensive State Cancer Plans Committee. Under Governor Ridge's leadership, the NDC helped spur the creation of a State government clearinghouse for cancer control best practices by working through the National Governors Association. At the Sixth Biennial Meeting of the NDC last month, Governor Ridge challenged all States to develop and implement cancer control plans that address surveillance, detection, treatment, prevention, and research. The goal is for all States and territories to develop comprehensive cancer plans by 2003 and implement those plans by 2005. Toward this goal, the Governor introduced an action plan that encouraged all States to customize their approaches to cancer by developing and implementing data- and stakeholder-driven State cancer plans. He also challenged each State to establish a nationally certified cancer registry as an essential element of its cancer plan. By promoting the development of State cancer plans, the NDC can leverage its leadership and influence by fostering a shared vision with Federal and State organizations that play a critical role in cancer plan development. Comprehensive cancer control plans offer the opportunity to narrow the gap between research and practice by enhancing our ability to acquire knowledge, create new technology, and make the best use of resources.

- It is also imperative to use research to determine and promote best practices and to continually evaluate their effectiveness based on that research.

MS. LORA M. RHODES

Background

Ms. Rhodes, a social worker, is Coordinator of the Advocacy and Survivorship Program at the Kimmel Cancer Center, Thomas Jefferson University, in Philadelphia, Pennsylvania. She has worked with hundreds of families facing cancer. She also works with a very active cancer advocacy committee at the Cancer Center. Through this committee, the Center has been successful in involving cancer survivors and family members in every aspect of cancer care, from basic research to patient care.

Key Points

- Many people are reaping the benefits of the amazing advances that have been made in the prevention, early detection, and treatment of cancer. People are living full and healthy lives today with diagnoses that just 10 years ago meant almost certain death. However, these advances in medicine have brought with them an even more complicated set of social and financial circumstances. It also seems that as sciences advance, the “line in the sand” that separates those who benefit from those advances from those who are left behind has become deeper.
- Myriad barriers prevent some Americans from getting the best possible cancer care. One of the most important of these, but an issue that seems to garner little attention, is the struggles faced by low-to middle-income working people when faced with a cancer diagnosis. Typically, when we think of those who are most vulnerable in terms of socioeconomic status, we think of those living in poverty. However, in terms of access to quality cancer care, the un- and underinsured working poor are sorely underserved.
- A diagnosis of cancer is financially devastating to a family. At particular risk are low-to middle-income families and young families who either have never earned enough or have not worked long enough to create their own financial safety net, yet they make too much to qualify for most State cash and medical assistance programs. Also, when only one earner provides both the income and the medical insurance for the entire family, a diagnosis of cancer is financially catastrophic. Many families live from paycheck to paycheck with little left over for savings. Most working Americans are ill equipped to handle the added financial burden a cancer diagnosis brings, including the high cost of medications and insurance copayments, as well as the hidden costs of cancer not covered by insurance, such as added transportation and childcare expenses. Many of us are one serious illness away from poverty.
- Financial burdens can affect access to cancer prevention and treatment in several ways. First, people who know what a diagnosis of cancer could do to their family financially sometimes ignore symptoms and do not seek medical care and, therefore, cannot benefit from the advances that have been made in early detection. For example, Ms. Rhodes worked with a man in his early 30s who denied headaches and dizzy spells for over a year because he was afraid he would lose his job as a roofer and be unable to provide for his wife and 4-year-old son. He was diagnosed with a brain tumor only after he had a seizure on the job.
- After diagnosis, some people avoid treatment or discontinue treatment early because of the fear of medical costs compounded by lost wages. One such case was a father of three young sons who was diagnosed with colon cancer at a very early stage. He was recommended for a proven protocol of surgery followed by adjuvant chemotherapy and radiation. He had surgery but discontinued

chemotherapy after one cycle because he did not feel he could afford to take time off from work. His cancer recurred less than a year later.

- Changing the Social Security Disability program could improve the quality of life of thousands of families facing cancer and effectively remove at least one financial barrier to quality cancer treatment. The Social Security Disability program was set up to protect working individuals who become disabled and are no longer able to work. The problem with this program is that it does not provide medical insurance. Disabled individuals are not eligible for Medicare until they have been disabled for 2 years. People receiving Social Security Disability have a difficult time getting insurance from other sources for several reasons. Typically, Social Security Disability payments place people slightly over the income eligibility limit for State Medicaid programs. People with excess income (by Medicaid standards) may still qualify if they go through a complicated process in which they spend down their income every month by paying out of pocket for medical expenses, leaving them with just under \$700 to cover all their other household expenses. Only then are they eligible for Medicaid to cover any other medical costs they incur for the month. In addition, employers usually do not extend insurance coverage past the 3- to 6-month period of short-term disability. Employees can purchase COBRA insurance; however, this additional expense—often \$200 for a single person, several times that for a family—is impossible for most people to afford at a time when their income is cut by at least 20 percent. Therefore, people who have worked their entire lives and are suddenly unable to work because of a cancer diagnosis are in the absurd position of being without health insurance at a time when they need it more than ever.
- Working class people are often put in the position of having to choose between making a mortgage payment and paying for health insurance.
- Ms. Rhodes recounted the case of a 45-year-old African-American woman who was the mother of three children: a 14-year-old daughter, who was a high school student; a 19-year-old son, who was a full-time college student living at home; and a 22-year-old son who lived on his own. She had worked in a commercial bakery for 25 years. In 1990, she was diagnosed with breast cancer and underwent surgery followed by radiation, missing only 2 weeks of work. In 1998, she was diagnosed with metastatic breast cancer. She worked for several more months until her illness left her unable to work. She applied for and received Social Security Disability. Her employer stopped paying her health insurance 6 months into her disability. When working, her monthly income was approximately \$1,500. Her monthly income on Social Security Disability was just under \$1,300—well over the income limit to qualify for Medicaid. The cost of her COBRA insurance was \$350, leaving her with just \$950 to cover all of the household expenses for herself and her two dependent children. While she was undergoing treatment to try to save her life, she was faced several times with the threat of her gas and electricity being cut off. She had to give up her car and rely on family and friends for transportation, and she almost lost her home. As she fought for her life, she also had to fight off creditors. While many factors went into her decision to discontinue treatment, fatigue from this incredible financial strain was a major reason she discontinued chemotherapy and entered hospice care. Much of her financial stress could have been avoided if she had been eligible to receive medical assistance—either Medicare or Medicaid—when it was determined she was disabled.
- Because advances in medicine have made cancer a disease that is both treatable and curable, it is more important than ever that no one be denied access to those benefits because of limited finances or inadequate insurance.
- Cancer survivors need to have a voice at the local, State, and Federal levels. Many of the answers to these complicated issues can be found in the experiences of those who know firsthand what it means to face the frightening territory that a cancer diagnosis brings.
- Ms. Rhodes read into the record a poem written by a cancer survivor about his experience in the radiation treatment waiting room at Jefferson Hospital.

Recommendations

- Possible solutions to relieve the financial problems faced by low- and middle-income people with cancer include: (1) shortening the waiting period for Medicare from 24 to 6 months so there is no gap in insurance coverage for people with a short-term disability benefit through their employers; (2) requiring employers to offer long-term disability insurance with health insurance to cover the 24-month waiting period before Medicare takes effect; and (3) allowing individuals on Social Security Disability the option of purchasing Medicaid at an affordable sliding-scale fee. Though just a few of the possible solutions, these changes would have a major impact on people facing cancer who cannot afford to purchase health insurance yet clearly cannot afford to be without it.

DR. DEBORAH WATKINS BRUNER

Background

Except for skin cancer, prostate cancer is the most common cancer in men, with almost 200,000 new cases estimated in 2001. Prostate cancer is the second most frequent cause of death among men. A man in the United States with average risk has about a one in six chance of developing prostate cancer. African-American men have twice the prostate cancer risk of other races in the United States, but, more disturbingly, African-American men have the highest risk of prostate cancer in the entire world. African-American men also have a lower 5-year survival rate, once treated, compared to other races (about 75 percent survival in blacks versus 90 percent in whites).

Key Points

- The Fox Chase Cancer Center has developed a state-of-the-art prostate cancer risk assessment program. The program has many objectives, but basically, it is trying to develop a registry for men at risk and their families. This program is not for men at regular risk, but for younger men, 35 to 69 years of age. Risk is defined by age, family history, and race. The program is providing education and counseling and will study a variety of research variables—including why men are at risk—and will assess outcomes. To enroll in the program, men are required to provide their insurance information. The program bills the insurer for services provided. Uninsured men are eligible for the program, but their participation is dependent on the availability of research dollars. Although only 14 percent of the program's catchment-area population is African-American, more than 50 percent of program participants are African-American. This represents an unprecedented level of success in patient accrual in screening or research programs. The program made a firm commitment at its outset to recruit men at high risk.
- To date, the program has screened about 275 high-risk men. Most of the participants are middle income, though the African-American men have slightly lower incomes and education. The mean age of participants is 48 years old; the mean age is the same for African-American and Caucasian men.
- The mean age of Caucasian program participants with cancer is 55, but among African-American participants, the mean age is 49—a very young age to have prostate cancer. The program is working with men with prostate cancer who are worried about fathering children; this has not happened before. However, as diagnostic tests become more sensitive, prostate cancer is being diagnosed more frequently in, and among a larger percentage of younger men, especially high-risk men. In addition, prostate cancer in younger men appears to be a more aggressive disease than in older men.
- To help reach the target population successfully, a minority consultant was hired to help develop the messages the program wanted to communicate. In addition, program brochures and radio ads using

these messages were tested in focus groups of African Americans to determine if the proposed messages were appropriate and were reaching the intended audience.

- There is much to be learned from the business community about marketing health programs. The prostate screening program employed “relationship marketing” in its strategy. Rather than using health professionals in the radio ads, the program used an African American whom the target audience was more likely to identify with and trust. These radio spots were targeted to stations with significant African-American listenership. Radio has proven to be the most effective communication channel for this population; overall, 57 percent of the people coming to the program had heard about it on the radio. Conversely, the program has had little success with television or newspapers. Messages aimed at relatives of potential patients have been somewhat successful. A multitude of other methods were tried as well. Radio ads brought in about 78 percent of the African-American men in the program. Among the Caucasian program participants, radio ads and relatives each brought in about 20 percent of the patient population. Radio works, but it is expensive: about \$8,000 to \$10,000 to run a 15-second spot for 2 weeks.
- Other recruitment strategies included setting up the program in the Pennsylvania Community Network hospitals. In addition, the NCI now has a database that includes demographics by ZIP code; this database is helpful in targeting particular populations or cultures for cancer awareness programs. This information has also been linked with marketing databases.
- The program is also developing organizational relationships. For example, a relationship has been established with Kappa Alpha Psi (an African-American fraternity). Marketing efforts are also being targeted specifically to women. Many women call to sign their husbands up for screening. In addition, many husbands call and say, “I’m calling because my wife made me.”
- An important lesson learned by the program is that strategies must be tailored to the community. The challenge is to find what works in a given community. For example, the literature suggests that recruitment through churches is effective in reaching minority patients; this was not true for this program. Similarly, fitness centers and barbershops proved not to be useful recruiting sites.
- It is important to realize that awareness and recruitment require money and labor and that these efforts must be ongoing.

Recommendations

- Dollars must be allocated specifically for cancer awareness. Recruitment funding gets diluted in the overall issue of funding for access and related issues, but even with the best access, if people are unaware of the service and the need for it, they will not come in.
- Women are the gatekeepers to family health and should be included in cancer screening recruitment efforts, even when the target population is men.

MS. ELNORA R. MARSH

Background

Ms. Marsh began to experience back pain in June 1988. Her physician performed a kidney scan, which was negative. She was sent home with a pat on the back and the assurance that she was just under stress because her husband had suffered a stroke. After Christmas of that year, Ms. Marsh was still experiencing pain, though in another location, and was excessively fatigued. She returned to the doctor, and it was determined that she had an ulcer. The doctor also said that she had a malignancy but refused to discuss it with her that day because he had the flu and was leaving the office. Two days later, still not having heard

from her doctor, she returned to the office to see the other doctor in the practice. This physician confirmed that she had an ulcer, but no malignancy.

Ms. Marsh continued to have pain and returned a third time, asking for a breast examination because she felt something suspicious. The doctor claimed he could not feel anything unusual. Ms. Marsh demanded a mammogram, which she received. The mammogram showed an abnormality, and she was referred for a biopsy a month later. However, the facility to which she was sent was a 1½-hour drive from her home. All of her x-rays had been lost when the doctor's office sent them to the biopsy facility, and therefore, the biopsy could not be performed, and she had to repeat all of the films and other tests. When she finally had the biopsy, it showed two tumors. She was asked why she had not taken care of "the first one," which was believed to be about 4 years old, but Ms. Marsh had never been told about it. Still, she was assured that because she had pain, it was unlikely that she had cancer, and that there was no hurry about proceeding. When she had surgery 9 days later, the recently discovered tumor, which was cancerous, was removed, but the original tumor was so large that it could not be removed. Ms. Marsh went home for a week, then returned and asked to have a mastectomy. At that point, she was given up to 2 years to live. Since then, she has had two episodes of skin cancer, and her marriage has ended, but she has been free of breast cancer and has survived for 12 years.

Ms. Marsh noted that the costs associated with her breast cancer diagnosis and surgery drained the family's savings. In fact, the hospital refused to release her until she had paid the \$8,000 her insurance did not cover. Currently living alone and with a low income, she is experiencing the same problem. After 12 years, she went to get a new prosthesis and two new bras (at \$84 each), for which she had to pay at the time of purchase; she had to borrow the money to get these items. In addition, the insurance company disallowed \$131 of the cost because the prosthesis provider was not recognized for reimbursement. She feels she was misled when she was told these items would be covered by her insurance.

At this time, Ms. Marsh struggles with diabetes and weight gain related to the diabetes and her cancer. She tries, however, to focus on the things she can do and conducts talks at health fairs to try to raise awareness of breast cancer. She joined a breast cancer support group, which she has found helpful.

Ms. Marsh was an original member of the Appalachian Leadership for the Coalition, a group working to raise cancer awareness, improve access to resources, and reduce risk in the community. The Coalition has trained Amish women in the community to find lumps in their breasts, and men to check for prostate cancer. This was done through home visits, since many Amish do not go to the doctor. In some cases, Coalition members picked the women up and drove them to a neighbor's house where the training was conducted. In appreciation, the some of the Amish women made a quilt for the Coalition members. At parades and other events, the Coalition displays the quilt and dispenses packets of small peas the size of a breast lump a woman might find.

In addition, Ms. Marsh and her group are closely involved with ACS activities in the area, including promoting mammograms, conducting free breast and skin cancer clinics, conducting parades, and helping with the Relay for Life.

MR. ALBERT CALLOWAY

Background

Mr. Calloway, from Pittsburgh, Pennsylvania, found himself uninsured due to divorce prior to his retirement. He applied for coverage from another insurer but was turned down because he was found to have squamous cell head and neck cancer. The only coverage he could then get was prohibitively expensive.

The major medical center in his city indicated that his treatment would cost \$90,000 to \$100,000. He was asked for a downpayment of \$20,000 to \$30,000 and told he would also have to pay \$500 to \$600 per month. Particularly since he was now retired, such costs were impossible for him.

Though he was embarrassed at not having insurance, Mr. Calloway called various cancer-related organizations and applied for Medicaid, Medicare, Hill-Burton, and hospital charity programs trying to find a way to pay for his treatment. He did not have access to the Internet. Mr. Calloway found that for each program he was either too old, too young, made too much money, or did not meet some other criterion. He felt it was impossible to get assistance unless he had no financial resources left and felt that in that case, he would not even care whether he was treated or not. Ironically, after calling many of these organizations for help, he was solicited for donations.

Mr. Calloway was becoming overwhelmed by his failure to find any source of help. Finally, he contacted the Patient Advocate Foundation in Newport News, Virginia. Although it took some time, a patient liaison there was able to get Mr. Calloway an approved treatment recommendation from Medicaid, and he was able to begin treatment near his home in Pittsburgh. Between this time and his diagnosis, however, his tumor had grown quite large. In the course of his treatment, he lost a great deal of weight, had all of his teeth removed, and was fed through a stomach tube. He felt devastated and wanted to give up, but he credits his partner with helping him endure the treatment. He finished his chemotherapy last month.

Key Points

- There are many people who do not know where to turn for help in the event of a cancer diagnosis. More patient assistance organizations are needed, and people need to know they exist and how to get to them to get the care they need.

MS. VICKI BURKS

Background

The single parent of two children, Ms. Burks resides in Philadelphia, Pennsylvania. On her fortieth birthday in April 1996, she was diagnosed with primary amyloidosis (AL), a disease with similarities to multiple myeloma that infiltrates the vital organs of the body and mainly affects Caucasian males from 50 to 60 years of age.

Ms. Burks was devastated to receive the diagnosis of a rare and fatal disease. After recovering from the initial shock, she resolved to fight the disease but worried about what treatment would entail and who would care for her children. Her employment, financial security, and ability to support her children were suddenly at risk.

Ms. Burks asked her physicians at the hospital in which she would be treated where she could receive help or supportive services for herself and her family. She was immediately put in contact with a social worker and was amazed at how quickly this assistance was arranged. Ms. Burks later learned that the social worker was new, that she was her first patient, and that most patients did not receive assistance with such expediency. She also received excellent treatment and support from her treatment team. Ms. Burks also called Robert Casey, ex-Governor of Pennsylvania (now deceased), who had the same disease; he encouraged her to have a strong and good attitude about her treatment.

Most of the information and supportive services Ms. Burks received were provided or arranged through her social worker in the hospital. The doctor and home care nurse provided her with most of the literature about her disease, the research currently underway, and treatment options. Having this information helped calm some of her fears. She and her family also relied on hospital-based support services, including one

specifically designed to help children with a seriously ill family member. There were few community resources, and those that existed were not very accessible. Ms. Burks joined a hospital support group but found that when she stated the type of cancer she had, other members of the group had never heard of it.

Although the plans for her treatment were set, she could not start treatment for several months because she was receiving medical assistance, and the State agency was unfamiliar with her disease. They approved treatment that was less than what her doctors said was required. After further State investigation of her case, she was approved for and received 100 hours of chemotherapy over a 10-month period. She applied for a bone marrow transplant that could put her disease into remission approximately one year in advance of the target date. She was rejected based on a regulation and the fact that medical assistance did not pay for experimental or investigational procedures not in accordance with customary standards of medical practice or not commonly used.

Ms. Burks felt her life and that of her children had been reduced to the language of a regulation because she did not have a common disease. However, having experience as a community activist, Ms. Burks solicited letters from her State Senator and Congressman. She also was assigned an attorney who would assist her pro bono. Eventually, with this support, she prevailed. Ms. Burks wonders if she would have received the treatment she did had she lived in a different city, had a different insurance plan, or been of a different race.

Ms. Burks will soon celebrate her fourth year of survivorship.

Key Points

- Newly diagnosed patients often cannot think clearly or focus on the many changes that will immediately take place. This is where advocates and social services are needed, especially for people and families who do not have a tenacious will to fight for life.
- Any fatal illness can or will change the course of our lives. An important factor that is often overlooked or disregarded is that if a person becomes ill or dies, this misfortune affects not only that individual, but all of the people in that person's life, such as family members, coworkers, and community residents.
- Life is not a commodity. It is a precious gift that has been given to us. We appear to place such a low value on a person's life that an individual cannot receive proper care if it does not make a profit for a company. Laypersons should not be allowed to decide who gets treatment and who does not. Only a medical professional familiar with the relevant terminology and procedures should be part of a qualified team that makes decisions about what treatment is appropriate for an individual patient.

DISCUSSION—STATE OF PENNSYLVANIA

Key Points

- If a man participating in Dr. Bruner's prostate cancer screening program is found to need treatment, and he is insured, his insurance company will be billed. If he is uninsured, a social worker is assigned to find and arrange a source of treatment (e.g., Medical Assistance), and the program has a certain amount of funds set aside to pay for treatment directly. Because of the controversies about prostate cancer treatment options, the program also includes a health education program and a detailed informed consent process and counseling mechanism (including genetic counseling) to clearly explain the options to men who contact the program for screening. For those who need treatment, it is explained again by the physician. Currently, the program is supported by research funds; recognizing that this form of support will eventually be discontinued, the program is working with the Department of Health to find ways to make these programs viable when the research funding ends. It must be

understood that, as in any business venture, program startup requires upfront funding, but the hope is that it will eventually become cost-effective.

- The Pennsylvania Cancer Control Plan is a major element in the strategy to bring research results into practice. The statewide Area Health Education Centers, also funded by the Department of Health, conduct clinical and professional education to transfer new knowledge to the medical community. In addition, the cancer centers in the State are working with the Cancer Alliance to help disseminate new information throughout the State. The State has put a lot of money into research, including funding for health services and population-based research, as well as funding for patient costs associated with participating in clinical trials. One missing element is a low-cost adult insurance plan; it is hoped that the State legislature will soon pass a bill enacting such a plan. States could use assistance from the Federal Government in determining the extent to which procedures are experimental and how to integrate them into the payment stream. Currently, such processes are redundant, esoteric, and expensive throughout the country.
- Pennsylvania is initiating a significant minority health initiative in which community health partnerships will be funded to create linkages in communities and better use cancer registry data (or to create registries where they do not exist) to determine the extent to which people are getting screened and diagnosed at late stages and to determine the cause of disparate outcomes. Regional reports are being prepared on these and other issues and will be discussed with the cancer institutes that cover each area, the medical societies, the hospitals, the ACS, and public health authorities. This information helps identify issues at the community level; then, local organizations can share resources to fashion solutions tailored to the local situation.
- Mr. Calloway explained that the Patient Advocate Foundation was able to get him spend-down approval from Medicaid so that he could qualify for the program. In his own contact with the program, he was told that he was over the limit in terms of both income and age; he was not told about the spend-down provision. In addition, the Foundation was able to get approval for his treatment at a facility that was more patient-oriented than the major medical center with which he initially dealt. Without this assistance in navigating the health care system, he might not have gotten the care he needed.
- Ms. Marsh noted that her husband had had a massive stroke at age 36, which left him paralyzed and blind for 18 months. His care and the cost of raising their four children had expended the savings they had accumulated in 6 years of marriage. They started over, but experienced a tornado, a flood, and a fire in a 5-month period. Thus, they had to begin again to build some security, and Ms. Marsh had by this time become philosophical, viewing these events as life hurdles to be overcome. When she was diagnosed with breast cancer, it was just another hurdle. However, she and her husband can no longer live together because with her limited mobility, she cannot care for him. She also indicated that she had gone to the welfare office for help but was told she had too much money to qualify for food stamps. Ms. Marsh noted the irony that for 9 years, she had taken in foster children in her community but could not get help herself in a time of need. When the little money she had was gone, she went back to Welfare and got assistance for one month, which enabled her to recover enough to again become self-supporting. She is living payday to payday. Her church and other community groups have helped on occasion. Ms. Marsh believes that you have to have the will to survive to find the help you need. She also noted that the doctor who missed her cancer for several years is still the director of a hospital; she knows of three of his patients who had the same experience with this physician and who died, and she wonders how many more he has missed.
- Ms. Rhodes confirmed that among the patient population she sees, it is common for patients to be faced with the choice of making their mortgage payment or paying for health insurance.
- Ms. Burks acknowledged that not all patients may be able to access their elected representatives with the same ease she experienced, because she had been active in her community and had met these

people several times in the past. In addition, her physicians encouraged her to be very proactive on her own behalf. She believes when it comes to life-and-death situations, an elected official should do whatever he or she can to help the affected person.

- Dr. Freeman noted that diseases like cancer always occur under human circumstances and that it is not enough to understand the science of the disease. Testimony such as the panelists have provided is important to understand these human circumstances. Society must take the risk to solve these problems and spend the money it will take to improve quality of life and survival.

STATE OF VIRGINIA

Presenters

Dr. Karen Connelly

Ms. Phyllis Katz

Mr. Jarvis Kuo

Mr. Joshua Sundquist

Ms. Linda Sundquist

Ms. Susie Miller

MS. KAREN CONNELLY

Background

Cancer is the second leading cause of death in Virginia. Blacks have a higher incidence rate than whites, and males have a higher incidence rate than females. Blacks tend to be diagnosed later, leading to poorer outcomes and increased mortality rates. For all cancer sites combined, age-adjusted incidence rates are stable for whites and are improving somewhat for blacks. Though statistics suggest that the combined rates for all minorities are lower, this reflects an inadequate reporting system; they do not necessarily experience less cancer than the rest of the population.

Lung cancer rates, though still highest for blacks, are declining. Conversely, colorectal cancer rates are rising for reasons unknown, but the same disparity between blacks and whites exists as for lung cancer. Breast cancer is increasing among white women in the State, but decreasing among black women.

Of Virginia's 95 counties, 47 are federally designated as health professional shortage areas, and 11 percent of the population lives in these areas, meaning that there are not enough health care providers for the population.

Sixty different languages are spoken in Virginia—most in Northern Virginia. In this diverse population, cultural and traditional myths and beliefs exist, but these are not well understood in terms of how they create barriers to care. In addition, some people are intimidated by the health care system.

Twelve percent of the population is uninsured. Inability to pay and lack of insurance are major factors keeping people from receiving the most appropriate care. In Virginia, 74,000 women between the ages of 40 and 64 are underinsured and below 200 percent of the Federal poverty level. Other vulnerable populations include migrant workers, the homeless, low-income persons, and the elderly. Lack of transportation is a major contributor to underservice, especially in the rural and mountain areas in western Virginia. Tertiary medical care centers are located throughout the State, but some people have to drive 400 miles to reach this care.

Virginia is working hard to establish local coalitions and services in the belief that initiatives need to be at the neighborhood level. Tobacco-related initiatives are aimed primarily at youth smoking prevention. It is believed these efforts will lead to lower lung cancer rates in the future.

Virginia has a Breast and Cervical Cancer Early Detection Program, but the need is much greater than the available program resources. Similarly, passage of the Breast and Cervical Cancer Treatment Act is a step toward providing treatment funding, but the need for this support also outstrips available resources. An Office of Minority Health has been established in the Health Department. This office works with community-based organizations, and its greatest successes have been with faith-based organizations, which respond strongly to prevention efforts.

Virginia has established a partnership of public and private organizations, including the State Health Department, tertiary medical centers, the private sector health and business communities, and insurers. The State also has a Cancer Plan Advisory Committee (CPAC), which wrote a cancer plan for 2001 through 2005. The plan provides guidance for cancer prevention, control, planning, implementation, and evaluation efforts. Its six goals are prevention, early detection, treatment, rehabilitation, palliation, and surveillance.

Ten percent of the State's funds from the Tobacco Master Settlement Agreement will be devoted to youth smoking prevention, including media campaigns, prevention programs, and research. This funding will amount to about \$15 million a year.

Virginia has long had an active cancer registry that has provided the data needed to support program planning and evaluation, monitor the cancer burden on communities, respond to citizens' inquiries about cancer in their communities, and conduct research.

Key Points

- Virginia has some of the best cancer centers in the Nation, but if people cannot get to them or do not have a mechanism to pay for services, these facilities are of no use.
- Health education at the local level is needed to encourage patients to change high-risk behaviors that cause cancer and to seek cancer screening tests. With education, the public will know when to ask for screening rather than wait for a physician recommendation.
- At the neighborhood level, diagnoses of cancer must be followed up more aggressively. Culturally competent and sensitive patient care is a priority because such care improves access to health care facilities. The State is also trying to make more support groups available.
- Patients need to know their rights and understand that they have alternatives. They should be able to make informed decisions about their cancer therapy and understand the risks and benefits of alternative and complementary cancer treatments.
- Additional funding is needed for cancer prevention and control. Other issues, such as communicable diseases, HIV, and West Nile virus, compete for staff and public attention.
- Other needs at the State level include: State legislation providing more support for screening and treatment programs; more collaboration between public health and managed care organizations; increased collaboration with medical and nursing schools to address protocols for cancer screening referrals and followup; better understanding by the public and legislature of screening recommendations; and increased collaboration between the CDC and NCI to provide cancer control resources to fund primary and secondary prevention.

MS. PHYLLIS KATZ

Background

In 1991, Ms. Katz, an attorney, had stage II breast cancer; in 1994, she was diagnosed with stage IV breast cancer. In the course of her own struggles with cancer, other cancer patients came to her with issues with which she, as a lawyer, could help. As a result of her own and these other patients' experiences, Ms. Katz found a cause, became involved in advocacy activities, and cofounded the Legal Information Network for Cancer (LINC).

The Richmond community responded enthusiastically to LINC; currently, more than 70 attorneys volunteer their services to anyone with cancer. An equal number of community volunteers help patients apply for disability coverage. No cancer patient who has contacted LINC has gone unserved.

The LINC program can easily be replicated in other communities.

Key Points

- Few people have the resources to handle the financial implications of cancer; most need help. Many cancer patients either cannot work at all or cannot work as fully as they would like. The financial cost of treatment causes some patients to choose between feeding themselves and their children and making insurance copayments—if they are lucky enough to have health insurance. Some patients have no money for food, rent, or heat and face cancer in a cold, empty house, with creditors at the door threatening eviction.
- LINC helps get health plans to pay what they have promised, helps patients get disability benefits when they are entitled to them, helps patients access Medicaid when they should be able to have it, and deals with many other issues not related to insurance.
- Ms. Katz recounted the cases of several of the patients LINC has assisted:
 - A woman with aggressive breast cancer was in treatment and had returned to work but was largely unable to perform her job. She was the single parent of a 16-year-old. Her employer wanted to know his rights and wanted to help her because he knew that if she lost her job, she would have no health care. This patient's heart was badly damaged by her Adriamycin treatment, and she eventually suffered heart failure, which put her into intensive care on a heart pump. While there, her former husband served her with papers for custody of her minor child. She survived another year, though deaf and blind, and was continually hounded by creditors.
 - Another breast cancer patient needed a bone marrow transplant. She was a Medicaid patient, and she learned that Medicaid in Virginia will not pay for transplants in anyone over age 21. Yet, she had been told by her doctor that only the transplant would save her life.
 - A State employee with a health care plan needed a bone marrow transplant for her leukemia and then learned that the coverage under her health plan excluded payment for donor testing. Each donor test cost \$1,000, and she had no money to pay for that testing.
 - A dying cancer patient, the single mother of very young children, called for help because she did not know where to find the fathers of her children. She was aware only of those who were in prison and did not want the children to go to these men; LINC assisted by making sure the patient's family would get custody of her children.

MR. JARVIS KUO

Background

Mr. Kuo was first diagnosed with cancer at age 10; he is currently 26 years old. At the time of his diagnosis, his family had just moved to the United States from China and did not speak English. The news of his diagnosis was very difficult for Mr. Kuo's family and added a huge financial burden to the immigrant family, which was already struggling financially.

The hospital at which he was treated tried without success to find a translator, so friends of the family had to take off work to translate and help with other matters. During these translations, words and meanings tended to be lost or changed, and the translators were unable to communicate the Kuos' feelings about their son's condition to his doctors.

As Mr. Kuo grew older and became more proficient in English, he became his parents' translator. This was very hard for him, as he was still a young child and had to translate bad news to his parents as to the progress of his treatment and the types of issues and procedures he would be facing. Out of respect for his parents, he would try to soften the news for them and assure them that everything would be all right. In fact, Mr. Kuo badly needed someone to soften the news for *him*. One of many such incidents occurred when he was 12 years old: He attended a meeting of the treatment team at which he was told that another abnormality in his chest had been detected on his x-rays and that surgery would be required to determine if it was cancerous. Mr. Kuo was shocked, but he had to translate the news to his parents. His memories of such moments remain very strong and painful.

The Kuos had no insurance upon arriving in America and were, in fact, unfamiliar with the concept of insurance. Fortunately, the hospital at which Mr. Kuo was treated accepted him as a patient, indicating that they would help find a way to pay for his treatment. Eventually, the family was able to qualify for Medicaid; however, Mr. Kuo's parents are still paying for treatment and related costs that were not covered by Medicaid—a continuing financial burden for them.

As Mr. Kuo grew older, he was able to advocate for himself. He became very vocal as to the treatment he needed and things he had to do to deal with treatment-related side effects and other issues. Mr. Kuo sustained numerous irreversible side effects, including cardiac damage and chronically insufficient magnesium levels—conditions for which he will be on lifelong medication. His treatment also rendered him sterile. A longstanding and continuing issue is the periodic need to replace his leg prosthesis to accommodate his physical growth and other body changes, as well as to replace it when it simply wears out. Although Mr. Kuo is now covered by an HMO, he must battle his insurer each time he needs a new prosthesis. The prosthesis he needs costs up to \$17,000, of which the HMO will pay only \$10,000. He has been contacting other agencies and groups to try to find ways to cover this cost differential. Mr. Kuo noted that this financial issue is likely to be lifelong.

Throughout much of his cancer experience, Mr. Kuo has been involved with groups that have helped him cope with his disease. One such group is Special Love, Incorporated, a nonprofit organization in Virginia that provides recreation experiences for 7- to 17-year-old children with cancer. At this camp, children with cancer are, to the extent possible, treated as normal and helped to have a normal camp experience. This camp was very helpful to Mr. Kuo when he was going through his treatment and was still new to the country. Later, he became a camp counselor. The greatest value of the camp, he believes, was the role models it presented of people he saw there living with the disease, who made him feel that he, too, could overcome his disease. Mr. Kuo was also helped by, and over the past 5 years has been involved with, the ACS and its Relay for Life.

MR. JOSHUA SUNDQUIST

Background

When Mr. Sundquist was 9 years old, he was very active and an avid soccer player. He began having pain in his left leg. His doctor said he was having growing pains. A year later, when the pain worsened, the doctor ordered an x-ray, which looked abnormal. The film was reviewed by seven doctors; most thought the film looked normal. Mr. Sundquist was taken to a pediatric orthopedic surgeon, and a bone biopsy was performed; the biopsy yielded only dead cells. After 6 weeks, the pain continued to worsen, and another biopsy was performed; this one showed that Mr. Sundquist had Ewing's sarcoma, a rare cancer affecting only about 200 young people annually. It had taken 2 months to establish his diagnosis.

The tumor was determined to have affected almost his whole femur, and he was given a 50/50 chance of survival. Mr. Sundquist began chemotherapy immediately and continued treatment for about 3 months. At the end of this period, however, the tumor had not shrunk appreciably. The family was faced with considering other options and sought a second opinion from a Ewing's sarcoma expert at Johns Hopkins Medical Center. Ultimately, Mr. Sundquist chose to have his leg amputated. The other option would have been to replace his femur with a metal or cadaver bone, but he would be able only to walk—any other activity would be dangerous, and any fracture of the leg would require surgery. Although amputation would have a serious effect on his life, he would be allowed to perform any activity he was able to and would feel more assured that the cancer was gone.

Mr. Sundquist recalled great sadness on the day of the amputation but actually believes he was sadder beforehand. Although quite young at the time, he resolved not to second-guess his decision and to make the most of whatever time he had left in his life. Because he never experienced the postamputation depression experienced by many amputees, a psychologist was sent to meet with him to determine if he was suppressing his feelings. Mr. Sundquist noted wryly that the psychologist drew pictures with him for a while and then left. His parents were charged \$400.

After the amputation, Mr. Sundquist continued chemotherapy for another 9 months, having 18 treatments over the year following his diagnosis; he spent almost 100 days in the hospital. In 1995, after he had finished all his treatments, it was determined he was in remission, and he has been cancer-free since then.

Throughout Mr. Sundquist's diagnosis and treatment, the family felt that the medical team had limited the amount of information they shared. The family researched Ewing's sarcoma on the Internet and repeatedly asked for more information. Although there was an overwhelming amount of information initially, this lack of information was a continuing source of stress.

The Sundquists experienced no problems with their insurer throughout Josh's treatment. His insurance coverage for his prosthesis has been very limited, however, paying only \$5,000 toward the cost of his artificial leg, which extends to the hip and has many parts. The most basic prosthetic costs \$11,000. Although the family has been able to meet the additional cost, the prosthesis does not afford Mr. Sundquist the range, comfort, or ease of movement a more sophisticated device would offer.

Mr. Sundquist attended the Special Love camp, receiving much-needed support. It was most valuable for him to see other young men (including Mr. Kuo) who had jobs and girlfriends and were living normal lives despite having artificial legs. He has returned to the camp as a counselor.

Since finishing treatment 6 years ago, Mr. Sundquist, now aged 17, has been going to school and lives what he describes as a normal teenage life. He has become involved in, and is successful at, ski racing and plans to move to Colorado next year to train full-time.

In addition, he has been involved in speaking about his cancer experience and in fundraising. He started a motivational program for middle school students and has given presentations in six Virginia schools over the past year.

MS. LINDA SUNDQUIST

Background

Ms. Sundquist is Joshua Sundquist's mother. In November 1998, about 4 years after her son was diagnosed with cancer, she was diagnosed with non-Hodgkin's lymphoma. She was treated at a small local medical center and received the standard chemotherapy for the disease. She was aware that new treatments were under investigation (e.g., Rituxan and monoclonal antibodies) at the University of Virginia and the large cancer centers, but such treatment was not available at her treatment site.

Ms. Sundquist's insurance company paid for most of her treatments, but after her treatment was completed, she began to have problems with veins in her legs that had been damaged by her treatment and were causing severe pain. Ms. Sundquist had had problems with varicose veins during her pregnancies, but these problems subsided after each birth. The insurance company refused to pay for care of the posttreatment vein problems, saying that it was a cosmetic procedure. Ms. Sundquist paid for five treatments on one leg, but because of the expense, she has discontinued these treatments. The insurance company also would not pay for any homeopathic or other complementary treatments that Ms. Sundquist wanted to explore since she had been told that her lymphoma was in remission but not cured.

Ms. Sundquist noted that Special Love is also a great source of support for parents of children with cancer, enabling them to get both professional and peer support. She also belongs to The Leukemia and Lymphoma Society, which sponsors a monthly support group at the local hospital; she has found this to be quite helpful.

MS. SUSIE MILLER

Background

Ms. Miller's husband has a rare mid-gut neuroendocrine tumor known as carcinoid syndrome. A disease that mimics many other conditions, it went undiagnosed for more than 20 years. Since the time he was a young man, Mr. Miller had had fatty tumors over each of his limbs and trunk; these were always dismissed as benign. In 1977, he was diagnosed with asthma after being hospitalized with severe bronchitis. In 1978, he developed irritable bowel syndrome and diverticulitis. Each time he experienced prolonged episodes of abdominal cramping and diarrhea, he was told to eat more fiber. Tests revealed nothing unusual. In the mid-1980s Mr. Miller developed esophageal spasms and reflux, as well as fluctuating glucose levels. He was given an antacid and told to watch his diet. Some years later, he developed high blood pressure and kidney stones. His HMO performed x-rays and other tests, but nothing was found. In the mid-1990s, his lung function began to deteriorate, and he was given a bronchodilator. Each illness was treated symptomatically. As a Foreign Service Officer, he was required to have rigorous biennial physicals, all of which he passed. No physician ever suggested that his illnesses might be interrelated.

Mr. Miller's illnesses continued, culminating in an episode of illness so severe that he needed urgent medical care. He had had two complete physicals in November 1996; cancer was not found, nor was any other major illness. Mr. Miller was taken to an urgent care center, where his history and test results were entered into a computer. The doctor told Ms. Miller that her husband needed to see a surgeon and be hospitalized immediately. From this point on, Mr. Miller's care improved. Within a few days, he was diagnosed with two unrelated types of cancer: carcinoid syndrome and kidney cancer. Mr. Miller was told that because his cancer was so advanced, he should get his affairs in order.

Some of the Millers' grown children were skilled at Internet research, and they located a carcinoid specialist in New York, Dr. Richard Warner. In April 1997, Mr. Miller underwent 14 hours of surgery—one of the tumors in his liver was more than 13 centimeters in diameter—and he had his cancerous kidney removed. He still has two small tumors and is being treated with Sandostatin.

Key Points

- Doctors need to be willing to learn about little-known cancers and diseases without feeling threatened. Likewise, doctors need to really communicate with their patients.
- Drug costs are exceedingly high and variable. The same Sandostatin can cost from \$1,400 to \$4,000 a month, depending on where it is purchased.

Recommendations

- Diagnostic and followup testing, as well as treatment, should be specified in a protocol that is followed by all doctors. The “wait and see” approach should not be applied to cancer.
- Insurance protection is needed for all people.

DISCUSSION—STATE OF VIRGINIA

Key Points

- LINC serves all of Virginia, but its network of attorneys is only in the Greater Richmond area, limiting direct attorney-client assistance in other parts of the State. At the time LINC was founded, it was the only organization of its kind in the Nation. There may now be a similar organization at one of the law schools in Southern California, a Disability Law Center dealing with similar issues affecting cancer patients. The San Francisco Bar had a similar program for a period of time for breast cancer patients. LINC has not been replicated; Ms. Katz hopes that by testifying about the program, it will encourage others to replicate it in their own communities.
- Some of the issues LINC deals with are not specific to cancer, but affect people with serious illnesses of all types. For example, the cost of care affects anyone dealing with a chronic disease. Loss of employment affects anyone with a debilitating disease. In addition, health plans today are businesses, not charities. Their purpose often runs counter to that of the doctor and patient; this extends to all types of care. However, what is unique about cancer patients is that they go through extraordinarily intensive care over a period of time. It is during that period when they are so vulnerable that their other systems (e.g., employment, insurance) fail. Most other illnesses do not have the intensity and duration of treatment that removes people from their normal supports in life and their normal abilities to function. For other illnesses in which there is long-term disability, Social Security Disability payment becomes available after 6 months, and both health care and income become more stabilized. But most of what happens to cancer patients occurs in the first 6 months, and there is no support—financial or otherwise—for them.
- Per-prosthesis insurance payments are typically limited. In addition, most health plans have a lifetime dollar limit on coverage. Mr. Kuo noted that while he is not especially athletic, his prosthesis must be replaced every few years. Like most people, although he is working full-time, his income is required to pay just his normal bills; it is difficult to save extra money for a prosthesis every few years.
- In Virginia, as in some other States, it has been necessary to advocate for specific legislative initiatives to resolve specific cancer care-related problems (e.g., bone marrow transplants for breast cancer, off-label use of drugs). Prosthetic coverage may be another such issue to which legislative bodies may respond if the insurance companies refuse to do so. Otherwise, people with chronic

illnesses or disabilities who are faced with reaching lifetime limits on their current health coverage may have no choice but to change jobs to get a new insurance plan and a new lifetime limit. There is no limit under Medicare, but one must be 65 years of age or older or disabled. Individuals such as Mr. Kuo and Mr. Sundquist are not considered disabled under Medicare's definition of disability.

- To help resolve translation problems, hospitals should be more knowledgeable about organizations in their areas that might be able to provide assistance when a patient from another country or culture requires treatment. Social workers could be the bridge to these organizations.

STATE OF WEST VIRGINIA

Presenters

Mr. Tom Sims

Dr. Charles E. Gabe

Ms. Judy Crow

Mr. Edward E. Chisholm

Ms. Pamela S. Rutherford

MR. TOM SIMS

Key Points

- Although the challenges faced by States may be similar, some of these manifest themselves differently in West Virginia than elsewhere. West Virginia is the only State whose boundaries lie entirely within the region known as Appalachia. Because the State is thinly populated, there are serious problems bringing the latest medical advances to all parts of the State. While some programs in West Virginia will pay for transportation, in some of the more rural areas, there is no transportation available regardless of income or willingness to pay.
- Even where services are available, they may not be accessible due to economic barriers. The financial barrier to access is present everywhere in the country, but is especially so in States like West Virginia that have lower socioeconomic status.
- Some women will not get screened because they know that if they are found to need treatment, they will not be able to afford it. West Virginia was one of the first States to take advantage of the Breast and Cervical Cancer Prevention and Treatment Act of 2000, making Medicaid coverage available for all women diagnosed with breast or cervical cancer who lack adequate insurance coverage.
- West Virginia also faces cultural barriers. The Appalachian culture, while having significant strengths, is sometimes characterized as fatalistic. Whether this fatalism is based on religious or other beliefs, people believe that they should take what life gives them and that everyone has to die from something. This attitude can keep people from seeking care when they should.
- Another illustration of the transportation barrier involves mobile mammography services. The largest health care provider in the State, Charleston Area Medical Center, was providing mobile mammography services to outlying regions. Vans equipped with mobile mammography devices traveled to rural areas of the State, and women would have the opportunity to get screenings near their homes. If problems were found, appropriate followup was arranged. However, in the late 1990s, the diagnostic equipment and the vans that carried it needed to be replaced. Because this service did not represent a major revenue source for the hospital, a decision was made to discontinue the mammography vans. Many people, including the wife of the Governor, were troubled by this decision. A combination of State and hospital funding was found to continue this service.

- Distance from care is a significant issue in West Virginia. For example, a woman from Pocahontas County, one of the State's sparsely populated counties, was diagnosed with breast cancer. To receive radiation therapy, she would have had to travel almost 2 hours each way to the nearest medical center. Because there was no way to arrange the 26 treatments that had been prescribed, she elected instead to have a mastectomy. Her situation is not unique.
- West Virginia also has barriers to obtaining basic primary care services. In addition, for a lot of West Virginians, the concept of preventive care does not extend beyond advice from family and some traditional folk remedies.
- Literacy is a problem in West Virginia. This is a fundamental problem; the best brochures will not help if people cannot read them.
- West Virginia ranks very high among the States in the percentage of population that is obese. Obesity is a physical and psychological barrier that keeps women from coming in for cervical examinations. To address this problem, the State's Breast and Cervical Cancer Program recently purchased for some of the rural areas eight special examination tables at a cost of \$12,000 each. These tables are built to serve both large and disabled women with greater comfort and dignity than standard examination tables.
- Best practices differ from State to State depending on each population's culture, economics, and transportation issues. The Federal Government can help West Virginia bring the best care to all cancer patients in the State by allowing States and localities a large amount of self-determination in how programs are administered. Allowing for more waivers and exceptions at the State level will help West Virginia reach all its people with solutions that work best for them. For instance, West Virginia needs to use more nurse practitioners than some other States. More lay educators and health educators are being trained, but their services often are not reimbursable.
- Although West Virginia is comparatively resource-poor, leaders in cancer control are working together through the West Virginia Comprehensive Cancer Control Coalition to create the infrastructure needed to advance efforts in this area. A comprehensive State cancer plan is being written.
- More research is needed to establish evidence-based approaches for reaching communities. The best services will not help if we cannot use social marketing and other emerging approaches in health promotion to get people to avail themselves of them.

DR. CHARLES E. GABE

Background

Dr. Gabe operates two radiation oncology centers in West Virginia.

Key Points

- In Appalachia, and throughout the country, there are physicians who are unwilling to do what is necessary to keep abreast of current standards of practice. This is unacceptable, since this information is readily available through a variety of media.
- Some primary care physicians, some lay people, and possibly some oncologists have a misconception about what cancer is and what is involved in its treatment. A common sentiment in Appalachia is that cancer treatment is worse than the disease itself. Another belief is that cancer is invariably fatal, so it is pointless to treat it. These attitudes contribute to delayed diagnoses and failure to detect disease when it is curable.

- The people of Appalachia are very proud people and like to do things their way; this culture is dissimilar to many of the cultures in the larger cities, and this can sometimes be a barrier to care.
- Untreated pain is a huge problem throughout this country. Cancer patients may endure severe pain because their physicians do not know how to treat pain appropriately. Patients may be either afraid or stoic. Because of these problems, some patients will die in pain; this is an unacceptable situation. Patients need to make their needs known, and they need to be very persistent about it.
- Greater efforts are needed to identify underserved populations, including the working poor and the middle class. Some of this population's employers do not provide health insurance. Some are self-employed and cannot afford to buy health insurance. Unfortunately, most of these people "fall through the cracks" because their income is just over government program eligibility ceilings. This situation must be addressed.
- Some physicians "cherry-pick"—they pick and choose which patients they will see based on their insurance status, the reimbursement rate, and/or the likelihood of cash payment (sometimes large cash payments are required before services will be rendered). Some practitioners will not accept Medicaid patients.
- In West Virginia, the mountainous terrain poses a barrier to care. Road access is poor, and public transportation is generally not available. Some residents cannot afford to buy gasoline or hire a driver.
- Unequal reimbursement between hospitals and freestanding facilities creates a serious barrier to quality care in rural areas. For example, intensity-modulated radiotherapy (IMRT) is a relatively new radiotherapy modality that will become the standard of care within 5 years. The technology costs \$750,000, and there is no CPT billing code for its use in the freestanding environment. This situation discourages capital expenditures and the development of new capital-intensive technologies in the freestanding setting—which discourages provision of quality care.
- Some hospital systems have blocked new providers from relocating to the area—to the detriment of the community—because those providers have been perceived as competition to these hospital systems. This is wrong.
- Medicare regulations prevent patients in hospice from receiving palliative chemotherapy or radiotherapy when such care would relieve pain and would not interfere with the hospice approach. Right now, hospice must pay for these services. This policy is not logical and penalizes the hospice.
- Differences in corporate cultures and competing health care systems make joint ventures or mergers almost impossible, to the community's detriment. These differences prevent facilities from taking advantage of economies of scale; therefore, it is difficult to improve the scope and quality of programs. Joint ventures that would be beneficial to the community should be encouraged. The Association of Freestanding Radiation Oncology Centers, which is committed to ensuring the availability and provision of high-quality cancer care in the community, has expressed its willingness to work with NCI in this area.
- West Virginia is not currently a physician-friendly environment, and out-migration is an ongoing problem. To address this issue, top-quality providers must be recruited, tort reform enacted, the provider tax (that taxes providers on their gross revenues) repealed, and caps placed on malpractice premiums.
- Patient access to clinical trials would be improved if quality providers were encouraged to affiliate with regional NCI-designated Comprehensive Cancer Centers.

Recommendations

- Quality standards should be established and enforced, including Board certification of providers, an oncology continuing medical education requirement, cancer program accreditation (through the American College of Surgeons Commission on Cancer) or accreditation of facilities (by the American College of Radiation Oncology or American College of Radiology), and other measures. Federal program providers not able to meet minimum standards should be excluded or reimbursed at a lower rate than those who take the time and effort to make sure they are providing quality care based on the most current knowledge.
- Multidisciplinary consultative approaches should be mandated. For example, in Michigan, there is a “breast law” stating that all patients diagnosed with breast cancer must be given a form published by the State of Michigan that explains all the treatment options, and they must read this form and sign off on it. Other States require that a multidisciplinary consultative service be at least sought. This is not feasible in some parts of the country; it certainly is not feasible in certain parts of Appalachia. This practice should be mandated, or at least encouraged, by legislation.
- Medicare premiums should be increased to those who can afford them. It makes no sense that the wealthy pay the same premium as someone who makes \$12,000 annually. Establishing a mechanism to determine an individual’s premium based on one’s income or estate would raise significant revenue for some of the additional programs that are needed.
- After means testing, cancer patients should automatically qualify for Medicare or Medicaid upon diagnosis.
- State and Federal programs should offer providers incentives to provide transportation and housing assistance for cancer patients who need these services.
- Incentives should be devised to encourage providers to accept all patients regardless of insurance status or ability to pay. “Cherry-pickers” should be excluded from Government-funded programs. Providers unwilling to accept Medicaid should be excluded from Medicare.
- The Certificate of Need (CON) process by which States determine whether a given medical service is needed should be modified. Currently, the determination is made via a formula based on the demographics of an area. In addition, quality measures should be added to the process to reward providers who demonstrate a commitment to providing quality care and accepting patients regardless of their insurance status. Facilities that do not properly use their status should lose their CONs.
- Reimbursement parity is needed for all types of quality providers. Freestanding and hospital providers of cancer services should be paid equally. The freestanding health provider is almost always more cost-effective than the hospital provider, yet hospitals receive higher reimbursements.
- Veterans Administration (VA) hospitals should be allowed to contract with multiple providers willing to provide care at a reasonable price. This will keep veterans from having to drive great distances to receive needed services when quality care is available close to home. The bidding and award process for VA contracts should consider quality measures, not just dollars.
- Medicare hospice benefits should be changed so that patients are able to receive all forms of palliative care while in hospice.
- We must work diligently to ensure that all Americans have access to high-quality, compassionate, state-of-the-art cancer care. Assistance must be provided to each patient in navigating through the complex health care system—which most patients do not understand. No one can be allowed to fall through the cracks.

MS. JUDY CROW

Background

Ms. Crow was diagnosed with breast cancer in 1997. She had never been sick in her life and did not believe cancer could happen to her. However, she detected a breast lump, and after denying to herself for a while that it might be a problem, she decided to go to the doctor. She had a mammogram, ultrasound, and a biopsy, which confirmed a cancer diagnosis. Having had little contact with the health care system, she found these procedures frightening. She elected to have a lumpectomy followed by chemotherapy and radiation.

Ms. Crow's doctor gave her limited information about her condition and suggested that she "had to die from something," and that if a bone scan revealed any metastasis, she should just go home and die. This attitude hardened her resolve to fight the disease. She was supporting two grandchildren and holding down three jobs. She researched her condition and also received support and guidance through conversations with breast cancer survivors.

Though she lived 32 miles from the radiation facility, Ms. Crow managed, with family and other support, to complete the 32 prescribed treatments. She continued to work throughout her radiation and the chemotherapy that followed it, experiencing no fatigue or nausea. Because her work involved conducting trainings and workshops for area families, she purchased a wig and false eyelashes prior to beginning her treatment. Ms. Crow was proud that she was able to continue her everyday life without change. She had always been the strong one in her family and had to continue in that role.

At the time of her treatment, Ms. Crow had health insurance, although the uncovered portion of her treatment costs was becoming sizable. Toward the end of her care, she was paying 100 percent of the costs, as she had exceeded the maximum allowable reimbursement. She worked extra jobs to help pay for her care.

After her treatment, Ms. Crow was put on tamoxifen. After taking the medication for 4 years, she began to feel that something was not right in her body. She went to the doctor to report her feelings. Her doctor dismissed her symptoms, but fortunately, the nurse prevailed upon the doctor to order ultrasound and other testing. Ms. Crow was found to have uterine cancer, most likely as a result of taking tamoxifen.

Just before this diagnosis, Ms. Crow was informed by her employer that its group health insurance plan was being discontinued; only 10 days' notice was given. She persuaded her doctor to perform a dilation and curettage (D&C) before her insurance was discontinued, and she hoped that no evidence of cancer would be found. Unfortunately, that was not the case, and Ms. Crow had to decide whether to go ahead with the needed surgery without insurance. She attempted to get medical assistance, but because she worked and had income, she was ineligible. Although she is now cancer-free, and her outlook is excellent, she has a bill of approximately \$20,000 for which she is responsible.

Ms. Crow expressed her hope that changes could be made to enable everyone in America to get the health care they need without kind of the financial burden she now faces.

MR. EDWARD E. CHISHOLM

Background

In 1999, Mr. Chisholm was diagnosed with colorectal cancer. His surgery involved removal of 12 inches of his colon, half of his rectum, and 22 lymph nodes, half of which were malignant. He was also found to have cancer in his left pelvic bone. Three weeks after the surgery, he began 200 hours of chemotherapy

and 32 radiation treatments. Although he stayed at the hospital to receive the chemotherapy, he traveled 120 miles per day to receive the radiation treatments.

After completing these treatments, he was to have a colostomy, but his doctor decided he could manage without this procedure. However, not having the colostomy left Mr. Chisholm in such pain that he had to take methadone. After a year, he decided to seek another opinion. A second tumor was found in his colon, and he required emergency surgery for an intestinal blockage. The colostomy was performed at that time, and Mr. Chisholm was free of pain for the first time in a year.

Six months later, additional metastases were found in Mr. Chisholm's lymph nodes and lungs. He began treatment again 3 months ago and has at least 3 more months of treatment ahead of him. One month ago, however, he was notified by his employer, the West Virginia Department of Transportation, that the State would no longer provide his medical coverage. Moreover, he was told that he should have been dropped from coverage some months before, and he therefore had to repay the State \$2,400 for premiums paid in his behalf.

Mr. Chisholm now pays \$600 per month in premiums to an HMO provider. He has been calling various organizations and agencies to try to obtain assistance, but without success. A two-time Vietnam veteran, he indicated that he would next seek help through the VA.

Further, his employer contacted him to inform him that after 2 years of disability related to a non-work-related illness, he would automatically be terminated in November 2001. Therefore, if he recovers enough to return to work, he will have no job waiting for him.

Mr. Chisholm and his family have drained their savings to pay for his care. Although he is receiving Social Security Disability payments of \$1,087 per month, most of that is expended on his health insurance premium, leaving little for food, utilities, and other bills. In addition, he requires several medications (injections to increase white blood cells after chemotherapy, pain medication, and antinausea medication) for which he must make a copayment; these copayments total nearly \$1,500 per month. He noted that the copayment for five antinausea pills is \$36; these pills sometimes do not carry him through the side effects following each chemotherapy session.

**MS. PAMELA S. RUTHERFORD
MR. ALAN RUTHERFORD**

Background

Ms. Rutherford, age 39, has an adult daughter and a 5-year-old son. She was diagnosed with cervical cancer in 1999. Previously, she lost a sister to breast and ovarian cancer and a grandmother to breast cancer. Her mother is the survivor of bilateral breast cancer.

Initially, Ms. Rutherford was diagnosed with cervical dysplasia. She was sent to an obstetrician/gynecologist, who performed a cone biopsy, cryosurgery, and laser treatments. Ms. Rutherford was insured through her employer; however, the insurance company refused to pay for her care, stating that it was a preexisting condition. Her doctor recommended that she have a hysterectomy and advised her to work out a payment plan with the hospital. The hospital demanded an advance payment of \$8,000, which Ms. Rutherford did not have.

It took 9 months from that time to find a doctor and a hospital to do the surgery on a payment plan. With the help of friends, family, and local churches, \$3,250 was raised to help Ms. Rutherford make a \$600 downpayment to the hospital and a \$2,000 downpayment to the doctor, who performed the required surgery in January 2000. The balance of the money was used for her medication, transportation, and

childcare so that her husband could continue to work. The surgeon charged half his normal fee. The total bill for her surgery was more than \$12,000. Prior to surgery, Ms. Rutherford applied for a West Virginia Medical Assistance card. She was denied because her family income (\$22,000) was too high.

Ms. Rutherford learned that she had invasive cervical cancer. She was referred to a major medical center in North Carolina, and it was determined that she needed radiation therapy. The medical center wanted her to undergo treatment there, but the center was a 10-hour drive from Ms. Rutherford's home. She decided to have the radiation treatments at one of the facilities operated by Dr. Gabe, who took her case despite her lack of insurance. He told her to pay what she could, when she could, and advised her to reapply for Medical Assistance.

Ms. Rutherford applied for a medical card again and was denied for the same reason. She was told that the only way she could get a medical card was to be 100 percent disabled, pregnant after having a hysterectomy, or separated from her husband. Ms. Rutherford and her husband seriously discussed the option of separation in order to pay for her treatments. In desperation, Ms. Rutherford contacted her State delegate to ask for help; in a little over a month, a medical card was issued from the same office that had previously denied her.

Ms. Rutherford noted that during the 9 months it took to find someone to perform her hysterectomy, she felt that her life was worth no more than a 2- by 3-inch health card. She knew her cancer was growing and feared she would not live to see her son grow up.

Her external and internal radiation treatment costs totaled \$59,000 and were covered by Medical Assistance. However, as soon as she finished treatment, Medical Assistance was withdrawn. Ms. Rutherford then had to pay out of pocket for her scans and blood work every 3 months. She noted that her sister, in the same position, could not pay for her followup care and probably died unnecessarily of her disease.

Mr. Rutherford had to quit his job with a local company because the company did not offer insurance. Fortunately, he was accepted into the International Brotherhood of Electrical Workers, which has a comprehensive health insurance plan. However, he has had to take a job out of town in order to provide his family with insurance. Now, after a 6-month preexisting condition exclusion for care related to her cancer, Ms. Rutherford's medical expenses are covered.

Key Points

- Ms. Rutherford noted that cancer care programs exist, but that the minimum age to qualify is 45; she knows her cancer could recur and fears that she may not live long enough to qualify for such programs. She believes no one should have to endure what she and her family have been through.
- It is in the national interest for people with cancer to be treated promptly so that they can return to being productive members of society.

DISCUSSION—STATE OF WEST VIRGINIA

Key Points

- Appalachian culture has both strengths and weaknesses, but a key factor in the culture is the isolation of the people, which in some communities seems to reinforce a distrust of professionals. Compared to many other parts of the country, Appalachia has less in- and out-migration. The fatalism common to the culture can be addressed by programs that are sensitive to this culture. As do Hispanic, Asian, and other special populations, the Appalachian population has a unique set of characteristics

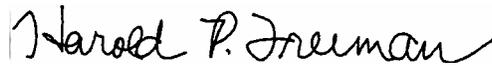
- Raising Medicare premiums for those able to pay and adding taxes on certain products (e.g., tobacco) are among the ways that revenue could be generated to pay for cancer care for all diagnosed persons.
- Dr. Gabe suggested that in Appalachia, some people with cancer are never treated. Often, it is because the needed care is not accessible, particularly in several West Virginia counties, but fatalism is also a major factor in whether people seek care. A common sentiment is: “This is the way it’s going to be; I’m going to die. I have cancer, and there’s nothing that I can do about it. God will take care of me.” These patients may eventually present at the emergency room with obstructions, bleeding, or other critical problems, but by that time, their disease is so advanced that death is imminent. This situation differs even from other parts of the country where many patients present with advanced disease but still receive some sort of treatment.
- Among the keys to improving this situation are implementing screening programs, educating the population, and educating physicians. Many physicians in rural areas simply do not know what to do when they see a certain constellation of symptoms or physical findings or are confronted with a cancer diagnosis. They have never heard the word *multidisciplinary*. They don’t know how to take care of pain.
- Precedents exist for immediate Medicaid or Medicare coverage upon diagnosis of a specific condition. People with renal failure automatically qualify for Medicare; under the recently passed Breast and Cervical Cancer Treatment Act, women screened through the BCCEDP will have their biopsies and treatment paid for by Medicaid.
- Dr. Gabe indicated his belief that medical providers have been given a privilege and owe it to society to volunteer part of their time. He would like to see a program specifically designed to help physicians do this.
- Cases such as Mr. Chisholm’s and Ms. Rutherford’s illustrate situations that are not acceptable in a society with the highest technology in the world to treat disease. People with a disease should be able to get treatment without bankrupting themselves, using up their savings, or losing their houses, jobs, automobiles, or dignity.

CLOSING REMARKS—DR. HAROLD FREEMAN

Dr. Freeman highlighted the issues raised in the 2 days of testimony. He thanked the speakers at this meeting—and at the previous six regional meetings—for their participation. In addition, he thanked the Panel’s staff for its assistance in planning and conducting each of the seven meetings. The Panel will prepare a report to describe in the most comprehensive and sensitive manner possible the many issues it has heard throughout the Nation. These findings and recommendations will be presented to the President of the United States and to Secretary Thompson.

I certify that this summary of the President's Cancer Panel meeting, *Real People, Real Problems—Why Don't All Americans Get the Best Available Cancer Care*, held May 24–25, 2001, is accurate and complete.

Certified by:



Date: 09/05/02

Harold P. Freeman, M.D.
Chair
President's Cancer Panel