

## **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?**

October 12-13, 2000  
Billings, Montana

#### **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 third in a series of seven regional meetings to explore issues that affect the ability of communities to provide cancer care—including prevention, education/communication, detection, treatment, diagnosis, rehabilitation, and palliative and end-of-life care—to people in the diverse neighborhoods of the Nation. This meeting brought together representatives from eight States in the northwest/mountain region to discuss these issues, the barriers faced at local levels, and local- and State-level efforts to address them. The State delegations, composed of up to six individuals, included cancer survivors, who described their personal experiences both with the disease and in obtaining needed information and treatment.

#### **MEETING PARTICIPANTS**

##### **President's Cancer Panel**

Harold P. Freeman, M.D., Chairman  
Dennis J. Slamon, M.D.

##### **National Cancer Institute**

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, President's Cancer Panel  
Jon Kerner, Ph.D., Assistant Director, Research Dissemination and Diffusion, Division of Cancer Control and Population Sciences

##### **Speakers**

Ferdinand Addo, M.D., Medcenter One Health Care (North Dakota)  
Jeanne L. Connors, Ph.D., Family Living Educator (Wisconsin)  
Kerry Dewey, M.A., Ed., Community Representative (Montana)  
Cathey Ducheneaux, Patient Liaison, Rapid City Regional Hospital Cancer Institute (South Dakota)  
Lisa Eades, Jason's Friends Foundation (Wyoming)  
Kathleen Murphy-Ende, R.N., Ph.D., Oncology Nurse Practitioner/Associate Researcher, University of Wisconsin—Madison (Wisconsin)  
Tess Frohlich, L.S.W., Project Coordinator, Matters of Life and Death Project—North Dakota (North Dakota)  
Delores Fallsdown-Geiger, Native American Outreach Education, St. Vincent Hospital and Health (Montana)  
Coral Houle, Community Representative (Minnesota)

Dawn M. Howerton, Health Educator, Wyoming Department of Health (Wyoming)  
Barbara Ingalsbe, Community Representative (Minnesota)  
Kristy Jones, Bureau of Health Promotion, Cancer Section, Idaho Department of Health and Welfare (Idaho)  
Ariiss Keckler, Community Representative (South Dakota)  
Chris Lorenzen, B.S., Director of Oncology Services, Wyoming Medical Center (Wyoming)  
Cynthia Mannering, Community Representative (Idaho)  
Mary Manning, Acting Director, Chronic Disease and Prevention, Minnesota Department of Health (Minnesota)  
Kathryn Mazza, Community Representative (Montana)  
David McCluskey, M.D., Twin Falls Clinic and Hospital (Idaho)  
Patricia McManus, Ph.D., R.N., Executive Director, Black Health Coalition of Wisconsin (Wisconsin)  
Mary Beth Meyers, Community Representative (Idaho)  
Gerardo Midence, M.D., Vice President, Billings Oncology Associates (Montana)  
Karl Musgrave, D.V.M., M.P.H., Director, Wyoming Cancer Surveillance Program (Wyoming)  
Pat Myers, Community Representative (South Dakota)  
Margaret Parry, Founder, Cowboys Against Cancer (Utah)  
Karen Johnson-Pochardt, Director, Cancer Services, Rapid City Regional Hospital Cancer Institute (South Dakota)  
Dolly Randles, Community Representative (South Dakota)  
Ceci Shapland, R.N., M.S.N., Executive Director, Women's Cancer Resource Center (Minnesota)  
Robert D. Speer, M.S., Regional Director, Cancer Services, Covenant Healthcare (Wisconsin)  
Michael Spence, M.D., M.P.H., Chief Medical Officer, Montana Department of Public Health and Human Services (Montana)  
Suanne Thurman, Administrator, Mountain States Tumor Institute (Idaho)  
Charles Tweedy, M.D., Director of Oncology/Hematology, Ivinston Hospital (Wyoming)  
Mary Alice Trapp, R.N., Native WEB Program Director, Mayo Clinic (Minnesota)  
Marge Visser, Community Representative (Montana)  
Walter Woods, Community Representative (South Dakota)

**OCTOBER 12, 2000**

**OPENING REMARKS—DR. HAROLD FREEMAN, CHAIRMAN**

In opening the meeting, Dr. Freeman noted:

- This is the third in a series of regional public meetings on *Improving Cancer Care for All—Real People, Real Problems: Why Don't All Americans Get the Best Available Cancer Care?* The first of these meetings was held in June at the Eppley Cancer Center in Omaha, Nebraska, and the second was held last month at the Vermont Cancer Center in Burlington. The concept for these meetings grew out of the Panel's 1999 evaluation of the National Cancer Program (NCP).
- In 1999, the Panel reviewed the history and evolution of the NCP and considered how the effort against cancer should move forward to more rapidly reduce the burden of this disease. In its report to the President of the United States, the Panel acknowledged the substantial progress made in combating cancer—particularly since the passage of the National Cancer Act in 1971. However, a significant disconnect still remains between research discoveries and delivery of the benefits of this knowledge to the American public.
- The Panel concluded that the equal importance of the research and delivery components of the national effort against cancer must be recognized and confronted. Also emphasized was

the importance of recognizing and addressing barriers that keep quality cancer prevention and care from reaching all of the neighborhoods in our Nation. Moreover, the Panel concluded that the unequal burden of cancer carried by the poor, ethnic minorities, and the underserved must be relieved.

- It is the responsibility of legislators and policymakers to enact laws and policies to ensure access to quality health care for all Americans. Cancer care standards must be updated continually to reflect current research findings. The results of cancer research must be readily available to health care consumers and third-party payers to ensure that proper care is rendered and reimbursed.
- Awareness of the cancer problem, as well as current knowledge about prevention and all aspects of care, must be increased through culturally appropriate public and professional education. Public pressure must be used to expand the national cancer effort to include sectors that traditionally have not perceived themselves to have a role in solving the cancer problem.
- The current and future cancer workforce requires greater training in state-of-the-art cancer prevention and care and should better reflect the diversity of our population. In addition, the cancer workforce must become more sensitive to cultural issues relevant to our diverse populations that affect the provision of cancer care of all types.
- Concerted action by all stakeholders is required to overcome the divide between the discovery and delivery components of the cancer effort. Failure to connect the research and delivery enterprises will impede our efforts to combat cancer, and progress will continue to be slow, uneven, and incremental. The Panel noted that this is not only a scientific and medical challenge, but a moral and ethical challenge for our Nation as well.

Today's meeting is focused on identifying what is required to ensure that the public receives the benefits of NCP research efforts. Toward that end, the Panel has posed the following questions to speakers:

- What is the disconnect between discovery/research and the delivery of proven cancer interventions to all populations in your State? Why does that deficiency exist?
- Who is underserved for cancer prevention and cancer care in your communities?
- Who are the vulnerable populations in each State?
- What is stopping people with treatable cancers from receiving the most appropriate treatments? Why are people dying from treatable cancers?
- In addressing local cancer issues, how have the economic, political, and public will been marshaled successfully?
- What do the States and communities need to do to provide proven interventions at the neighborhood level for cancer prevention, control, and care to people with cancer and to those at risk?
- What can or should be done at the national level to support local and regional efforts? What policy, legislation, and infrastructure changes are needed at State and local levels?

Of the eight States presenting at this meeting, South Dakota, Wisconsin, and Wyoming are currently identified by the Federal Employees Health Benefit Program (FEHBP) as medically underserved areas. North Dakota was only recently removed from the list. The designation of an area as medically underserved indicates that there are critical shortages of primary care physicians as determined by

comparing Department of Health and Human Services (DHHS) data on primary medical care manpower with the U.S. Census figures on State populations. If a quarter or more of the State's citizens live in areas with such shortages, that State is considered medically underserved.

This meeting includes a Town Meeting, to be moderated by John Bohlinger (Yellowstone Public Radio and a Montana State Senator). The Town Meeting provides an opportunity for public questions and comments. Several future meetings will be held, and an additional meeting is planned to explore international health system experiences and their applicability to the U.S. health care system. Findings will be discussed with Federal, State, and other stakeholders. The process will culminate in a report to the President of the United States in 2001.

**DIRECTOR'S REPORT—DR. JON KERNER, ASSISTANT DIRECTOR, RESEARCH DISSEMINATION AND DIFFUSION, DIVISION OF CANCER CONTROL AND POPULATION SCIENCES, NATIONAL CANCER INSTITUTE**

Representing Dr. Richard Klausner, Director, NCI, Dr. Kerner welcomed the participants and stated that:

**Key Points**

- As Dr. Freeman indicated, the overwhelming majority of NCI's resources are provided to extramural scientists and research institutions. Dr. Klausner is cautiously optimistic that legislation authorizing the Fiscal Year 2001 budget will continue the trend of increased investment in cutting-edge science, which will help NCI achieve its fundamental goal of developing interventions to reduce cancer incidence, morbidity, and mortality for all Americans.
- The rate of new cancer cases declined an average of 1.3 percent per year from 1992 to 1997. The cancer death rate decreased 0.6 percent from 1991 to 1995. That decrease accelerated to a rate of 1.7 percent per year from 1995 to 1997. Despite this progress, cancer remains a major public health burden. This burden is borne unequally by a number of U.S. population groups, particularly the poor and the underserved.
- Dr. Klausner created a new NCI investment challenge to reduce cancer-related health disparities. The centerpiece of NCI's initiative is the newly created Center to Reduce Cancer Health Disparities, which will be located within the Office of the Director and will be headed by Dr. Freeman. The Center will focus on special populations research from a socioeconomic and cultural perspective, but also will include a health policy component to take the knowledge attained through research and translate it into new policy initiatives benefiting those who bear the greatest cancer burden.
- NCI will invest in fundamental research to understand what contributes to these disparities. For example, a new Request for Applications (RFA) will be released to identify the broad social determinants of cancer health disparities. Since these social determinants do not relate exclusively to cancer, NCI is working with other NIH Institutes, such as the National Institute for Environmental Health Sciences (NIEHS), and with the Robert Wood Johnson Foundation (RWJ) to cosponsor this initiative, because problems contributing to the unequal cancer burden also contribute to other health problems.
- New resources will be provided for intervention research to reduce tobacco use, improve diets, increase physical activity, and increase the use of cancer screening services.

- NCI will expand its capacity to monitor cancer trends in different populations by expanding the Surveillance, Epidemiology, and End Results (SEER) program and collaborating with the Centers for Disease Control and Prevention's (CDC) national program of cancer registries.
- NCI also will expand training programs and provide infrastructure support for community-based participatory research. A recent initiative is the Special Populations Network (SPN)—NCI's first investment in community-based research infrastructure designed to build capacity within special populations to enable them to conduct their own research. One of the 18 funded programs is based in Rochester, Minnesota, under the leadership of Dr. Judith Kaur. The program focuses on comprehensive tribal cancer control through partnerships with the Native American Network for Cancer Control Research, NCI's Cancer Information Service (CIS), and the American Cancer Society (ACS).
- NCI plans to invest new resources to close the gap between cancer discovery and care delivery. The TRIO program—Translating Research into Improved Outcomes—will offer NCI-funded investigators the opportunity to apply for an additional year of supplemental funding for dissemination and diffusion of research results, provided effective outcomes can be demonstrated.
- Data-based decisionmaking—making better use of census, behavioral, and cancer data to motivate local action—is a key component in translating research into improved outcomes. For example, the Web site, [www.communityhealth.hrsa.gov](http://www.communityhealth.hrsa.gov) contains a community health profile of every community in America. As of 1998, approximately 1.75 million people residing in the 8 States testifying at this meeting lacked health insurance. The level of lack of insurance in these States ranges from 10 to 23 percent. In Yellowstone County (Montana), a number of chronic disease indicators are favorable relative to other, similar parts of the U.S.—for example, county residents have colon and lung cancer mortality rates lower than the national average. However, breast cancer mortality rates are higher in Yellowstone County than in the U.S. overall and compared with similar counties. The key is to determine how data such as these can be used to identify and address problems, to motivate communities and stakeholders to obtain resources needed to address the problems, and to implement solutions.
- The second part of TRIO involves promoting the adoption of evidence-based interventions and their dissemination to those who need assistance. NCI is working with the CDC, the Indian Health Service (IHS), other Federal agencies, and the ACS to format research evidence and to make it useful to clinicians.
- Special partnerships will be developed to identify local and regional infrastructure barriers. The lack of sufficient infrastructure may compromise the delivery of effective interventions to those who need help the most.

## **MONTANA**

### **Presenters:**

**Dr. Michael Spence**  
**Ms. Kerry Dewey**  
**Ms. Delores Fallsdown-Geiger**  
**Dr. Gerardo Midence**  
**Ms. Kathryn Mazza**  
**Ms. Marge Visser**

### **DR. MICHAEL SPENCE**

#### **Background**

Montana is the fifth largest State in area, spanning 762 miles from its northwest to southwest corners. Its population totals only 880,000. Half of the State is considered frontier, meaning there are fewer than three people per square mile.

#### **Key Points**

- For the past 5 years, the most common cancer diagnosis in Montana has been prostate cancer, followed by breast, lung, colorectal, and bladder cancers.
- Montana's Breast and Cervical Cancer Screening Program has increased the number of diagnoses of these two diseases. Montana's Lung Cancer Program has been oriented toward tobacco, and it is anticipated that Program activities will lead to earlier diagnoses and decreased lung cancer death rates. State data reveal equal rates of colorectal cancer among men and women. Men are not adequately screened for cancer, since their health care seeking behaviors tend to be problem-oriented and, therefore, episodic. Improved outreach efforts are needed to reach males with early detection services. No screening program exists to detect bladder cancer in either men or women.
- Montana's overall age-adjusted cancer death rates are slightly, although not significantly, below the national average. Nonetheless, a great deal of work remains to be done in this area. Cancer mortality is highest among those over age 60. Cancer is not a significant cause of death in children under 5 years old, but an increase has been observed in the 15- to 24-year age group. Cancer death rates rise precipitously at age 45, and then decrease among those aged 75 and older. Approximately 25 percent of deaths in the 45- to 75-year age group are due to cancer. In terms of total cumulative years of productive life lost, cancer far outstrips other causes of death.
- A survey was recently undertaken in Libby, Montana (a representative area of the State), to identify the role of health insurance in providing or limiting access to care. The survey indicated that approximately 21 percent of the population in the representative sample was uninsured. When those eligible for Medicare were eliminated, the percentage rose to 24, which is extraordinarily high compared with national lack-of-insurance rates. Not only is there a high rate of lack of insurance, but there is a significant level of underinsurance (e.g., extremely high deductibles) that makes preventive care unaffordable.

## **MS. KERRY DEWEY**

### **Key Points**

- Ms. Dewey, a two-time breast cancer survivor, believes that good cancer care is available in Montana; however, serious issues related to access must be addressed. These issues include access to financial resources, health care services, and information.
- Median household income in Montana is the fourth lowest in the Nation. Nearly one in five people is uninsured. When finances are limited, even basic health care is put off, and when health care is put off, cancer is not detected early.
- Although Ms. Dewey had health insurance, key aspects of her cancer care were not covered by her health plan, such as the cost of a wig; the cost of professionally led support groups to provide assistance in dealing with metastatic disease; and, most importantly, the costs associated with clinical trial participation. Despite having health care coverage, her family was forced to turn to its savings and the children's college fund to pay for approximately \$20,000 in nonreimbursed costs.
- Access to health care in Montana is particularly difficult, given that it is an extremely large State with a sparse population. The State has only 7 population centers, and 70 percent of the population lives in rural areas of fewer than 15,000 people. Eight counties have no primary care physicians. Montana has no Comprehensive Cancer Centers, only 20 Board-certified medical oncologists, and fewer than 10 radiation oncologists. In the western half of the State, there are no plastic surgeons performing breast reconstruction for mastectomy patients. Both this lack of specialists and geographic factors result in many patients receiving cancer care from primary care physicians rather than Board-certified oncologists. Ms. Dewey noted that she had to insist on referral to an oncologist.
- Cancer patients in Montana routinely travel great distances for care. One hundred miles or a half-day of travel is not uncommon. Many go out of state to the Mayo Clinic in Rochester, Minnesota; the Fred Hutchinson Cancer Center in Seattle, Washington; or to the M.D. Anderson Cancer Center in Houston, Texas. Travel times and distances are major factors in treatment choice decisions.
- The surgeon performing Ms. Dewey's first breast biopsy refused to discuss lumpectomy as a treatment option, stating that all of his patients who chose lumpectomy died within one year.
- Ms. Dewey was eager to find a clinical trial that would accept Stage IV breast cancer patients, but her own oncologist was not participating in any such trials. She located an appropriate trial at the NIH Clinical Center in Bethesda, Maryland, and agreed to travel there to receive treatment. She acknowledged that many patients would not have the resources to make this choice, even if they were aware of its availability.
- Lack of access to information is a key barrier to the receipt of effective treatment. At the time of Ms. Dewey's initial diagnosis, the Internet was not available as a resource, and there were no support groups in her area to provide assistance. She also experienced a 3-week delay in receiving a return phone call from the ACS in her area. Information is much more readily available today, but it is still difficult for many people to access the cancer-related information they need. For example, hundreds of people in Montana have no telephone service. Newly diagnosed patients are simultaneously trying to navigate the medical system and research current information on treatment. Consequently, many become frustrated,

overwhelmed, and often “fall through the cracks.” Moreover, although the institutions and agencies in Montana are small by metropolitan standards, Ms. Dewey found that many agency employees were unaware of the services available within their own organizations.

- Publication of the free *Montana Breast Cancer Resource Guide* has addressed much of breast cancer patients’ information needs. A second edition will be released this month for National Breast Cancer Awareness Month. It lists more than 100 services and providers in Montana offering help to women on breast health and breast cancer issues. Originally published in 1996, it fills a vast need for up-to-date, comprehensive information.
- Montanans are tough, pioneering people. Despite often adverse conditions, they tend to “suck it up and make do,” but this should not have to include making do with inadequate cancer care.

## **MS. DELORES FALLSDOWN-GEIGER**

### **Background**

The Women Reaching for Wellness program covers a large geographic area that includes seven reservations in Montana and one in Wyoming, as well as five urban centers in Montana. Ms. Fallsdown-Geiger joined the program in 1989 under a grant from the National Surgical Adjuvant Breast and Bowel Project. She is the Outreach Educator for the program. Other staff include a Program Director (an oncology nurse specialist) and a Data Case Manager.

### **Key Points**

- The principal reason American Indians do not receive the best available cancer care is fear stemming from a lack of education and awareness about cancer. Many Native Americans still believe cancer is contagious. In addition, an attitude of fatalism is common; Native Americans diagnosed on the reservations typically die from their cancers due to late diagnosis. Thus, the prevailing attitude is that seeking cancer prevention or early detection is pointless because death is inevitable. Additionally, a very powerful belief exists among many Native Americans that if they talk about cancer, they will bring it upon their reservation.
- Geographic access is a key barrier to care because the roads are particularly difficult to navigate, and the reservations are located in mountainous areas.
- Another barrier to access is the lack of culturally sensitive educational materials written for lower literacy levels. NCI has begun to examine the literacy levels of its cancer education materials, but much work remains to be done to meet population needs.
- Poverty and lack of community support make it particularly difficult for cancer patients to obtain needed assistance. Secrecy surrounding the disease results in a great deal of private and isolated suffering that continues until death. Issues related to poverty, such as the challenge of daily survival, far outweigh the importance of being screened for an asymptomatic and [initially] painless disease.
- Women must be educated that painless lumps can indicate the presence of breast cancer and that care should be obtained promptly if a lump is detected. This is an especially difficult concept for Native Americans to accept.
- The western medical approach cannot be used to create and implement effective cancer education programs for Native Americans. Educators must learn about their target populations through personal contact. Educational efforts must, to the extent possible, be

hands-on activities. Trusting relationships must be developed with the people, reservations, the tribes, and especially tribal health programs providing care to women. Educating and training a small number of women is the most effective education and dissemination strategy. This strategy recognizes that these women will transfer the information to their families and communities by word of mouth.

- In the development of the Women Reaching for Wellness program, many important lessons were learned through trial and error. Failure to use culturally sensitive materials resulted in materials being thrown away without being read. Program schedules and procedures were developed without due consideration of their impact on potential clients. Educational materials were not prepared at appropriate literacy levels, and there was resistance to changing ineffective teaching tools. Due to repeated reliance on inappropriate strategies, the same poor results occurred.
- Because of culturally based modesty, Native American women have a strong preference for female health care providers. Previously, female providers were few, but over the past 10 years, their number has increased considerably. Older women are unaccustomed to and uncomfortable with receiving cancer education through cable TV or video, preferring face-to-face contact in the education and care processes.
- The Women Reaching for Wellness program includes culturally sensitive motivators and incentives, such as Native American-style beaded ribbon pins and door prizes.
- Flexibility and continuous program modification based on community input is essential to ensure program effectiveness. Working directly with the community and collaborating with national, regional, and local breast and cervical cancer outreach efforts is essential. The program has collaborated with the Avon Foundation, the Susan B. Komen Foundation, CDC, the Montana Breast and Cervical Health Program, the Montana Tumor Registry, ACS, and the Native American Cancer Initiative. Working directly with tribal leaders and tribal health programs is the most important and productive way to achieve collaboration. In addition, through grants provided by some of these organizations, the program has been able to pay IHS for the cost of providing mammograms to Native American women.
- Development of culturally sensitive Wellness Celebrations is one of the best approaches to promoting wellness and increasing outreach. Celebrations shift the focus from sickness and disease to health and wellness, which is more culturally acceptable and, therefore, better received. To be successful, tribal leadership must be deeply involved in the cancer effort. Cancer support groups and healing circles need to be established for Native Americans. Celebrating life empowers cancer survivors.

## **DR. GERARDO MIDENCE**

### **Key Points**

- Millions of Americans diagnosed with cancer lack access to basic cancer care, which should be considered to include diagnostics, curative therapies, palliative care, hospice, and grief counseling for patients' families. Little research is conducted in hospice and palliative care, and little education is available for patients and their providers in end-of-life care. Fortunately, the Robert Wood Johnson Foundation and other institutions, such as the Academy of Hospice and Palliative Medicine, have funded the American Medical Association to provide physician education in end-of-life care. However much more education is needed.

- In addition, having access to care does not necessarily mean that the appropriate care will be delivered.
- Dr. Midence recounted the case of a 29-year-old female patient diagnosed with Hodgkin's disease. Lack of health insurance resulted in the loss of her home, her job, and her husband's job; the family was forced to move from Billings to Helena, Montana, to live with her family. After two relapses, this patient needed high-dose chemotherapy with stem cell transplant. The providers in Helena required that she pay \$45,000 before they would initiate treatment. She called Dr. Midence in Billings, where, fortunately, stem cell transplant could be performed without initial payment. She was able to receive the treatment she needed and now is cured. Although it took 5 years to recover financially from the experience, the family again has a home, and the patient's husband is again employed. Had she not been treated, she would have died.
- This patient's situation illustrates that people can reach a point at which they have lost everything—a situation they never would have believed could happen to them. But the current health care system does not help people get the care they need, primarily because of health insurance-related barriers such as Medicaid income and asset tests, Medicare age restrictions, exclusions for preexisting conditions, and waiting periods to obtain disability coverage through SSI or private insurance. In Billings, many families are in this type of situation, but they receive care nonetheless. Still, the pie can only be divided so many times.
- Regardless of where they live, veterans must receive cancer care at a Veterans Administration (VA) facility to be covered under the VA system. Veterans in Billings must travel to Salt Lake City, Utah, or to Denver, Colorado, and often remain in these locations for as long as 6 months to complete a treatment regimen. They are not allowed to be treated by local oncologists. Certain veterans receive only partial coverage of their care from the VA due to eligibility restrictions, and the VA does not sufficiently assist veterans in identifying alternative funding sources such as Medicaid, Medicare, or other third-party payers. Consequently, veterans suffer, and many die without care, because they are angry at the VA system for what they see as abandonment.
- Failure to address language and cultural barriers creates undue hardships for certain populations, particularly Native Americans and Hispanics. These issues limit access and prevent patients from accepting needed treatment. Providers may misconstrue patients' resistance as hostility or noncompliance, when the problem is a cultural issue.
- There is a significant lack of education in end-of-life cancer care. The lack of education about and access to alternative forms of care (e.g., home care for terminal patients) too often results in admission to intensive care units where palliative care is not provided and end-of-life issues are not sufficiently discussed.

## **Recommendations**

- Cancer-related research should be performed not only to improve treatment methods, but also to develop better ways to serve cancer patients across the full continuum of care.
- Reimbursement for cancer treatment provided in clinical trials should not routinely be denied because treatments deviate from current care standards. Clinical trial research is the pathway to improved treatment approaches, and lack of reimbursement should not deter patient participation.

- Hospice care should be available to all patients who need it, regardless of health care insurer. Neither the VA nor the Indian Health Service pays for hospice care; thus, these patients receive hospice services only through charity care.
- Politicians, policymakers, social workers, physicians, and all those involved in shaping the health care system should work together to improve the availability and delivery of end-of-life care.

## **MS. KATHRYN MAZZA**

### **Background**

Ms. Mazza, a 51-year-old community representative from Belgrade, Montana, was diagnosed with breast cancer in 1999. She is middle class, a homeowner, married, and primarily a homemaker, although she maintains the accounting, prepares tax documentation, and otherwise assists her self-employed husband in his business. Prior to her cancer diagnosis, both she and her husband had been healthy, active adults.

### **Key Points**

- Upon diagnosis, Ms. Mazza launched a personal campaign to research her disease and to identify alternative treatment approaches. Her research included Web-based searches, a literature review, and discussions with medical and radiation oncologists.
- Although she expressed interest in clinical trial participation, she did not fit the criteria for any of the clinical trials in her area. Because of concern about possible metastasis to her skull, her treatment regimen included breast surgery, two courses of chemotherapy, skull irradiation, and radiation to the chest wall.
- Ms. Mazza turned to God to assist her in deciding whether or not to seek treatment and where to receive care—either locally, outside the State, or outside the country. She decided to obtain her treatment from the only local medical oncologist—in Bozeman, Montana—and was extremely pleased with the quality of care.
- As a small business owner, Ms. Mazza described herself as self-insured; more accurately, she is uninsured because the cost of health insurance has been prohibitive. She and her husband did not qualify for any Government assistance programs and have thus been responsible for all of her medical bills. Through discussions with her providers, she has been able to negotiate discounts for her care, some of which have been substantial. In addition, chemotherapy drugs and most other associated medications were provided to her free of charge.
- Disparities do exist between the care provided in major urban settings and the care available in smaller cities and localities.
- Research should be undertaken to make it possible to determine with certainty the effectiveness of chemotherapy on an individual. Ms. Mazza indicated that she is currently cancer-free. She expressed concern about the costs of continued followup care, which will include checkups, scans, and, possibly, other tests.
- Despite the overwhelming generosity of family, friends, and providers, the out-of-pocket costs of her cancer care are significant. To help pay her medical debts, she has embarked on a new career as a real estate agent.

## **MS. MARGE VISSER**

### **Background**

Ms. Visser, a resident of Manhattan, Montana, was diagnosed one year ago with Stage III colorectal cancer. Her cancer was detected during an annual examination, and she underwent surgery to remove the cancer from the lining of the colon and two lymph nodes. Side effects of her chemotherapy were severe enough to require intensive care. She was cancer-free at her 1-year followup.

### **Key Points**

- Ms. Visser's husband is a self-employed rancher, and they are uninsured. Ms. Visser's cancer treatment expenses to date have totaled approximately \$40,000. Although she received some financial assistance from family members, the cost of her treatment has been a considerable burden. She is making monthly payments to her treatment providers to reduce this debt; however, much remains to be paid. Ms. Visser indicated she will soon return to work.
- She has participated actively in cancer support groups, including the Cancer Family Support Network.

## **DISCUSSION—STATE OF MONTANA**

### **Key Points**

- Montana has a Community Clinical Oncology Program (CCOP), the Montana Cancer Consortium, and the Billings Inter-Hospital Project, as well as access to the clinical trials of the National Surgical Adjuvant Breast and Bowel Project (NSABP). Patients also can access trials offered at academic centers and industry-sponsored trials. NCI's Physician Data Query (PDQ) database is an important source of information about available trials. When possible, treatment is provided locally, although in some cases, patients prefer to travel to receive care from a large institution. If appropriate care is not available locally, patients must travel to the site of care.
- Oncologists are located in Kalispell, Bozeman, Missoula, Billings, Great Falls, and Helena. However, 70 percent of the Montana population lives in other geographic areas, which lack not only Cancer Centers and oncology professionals, but also primary care providers. The lack of primary care providers makes it difficult to obtain an initial diagnosis and, when necessary, a referral.
- Active physician recruitment efforts are underway in Montana, but because the population is so geographically dispersed, it is difficult to attract either primary care physicians or specialists to the State. The issue of provider scarcity is routinely discussed with State legislators.
- Lack of insurance and underinsurance have a devastating financial impact on cancer patients and their families. In addition, Montana's unemployment rate is high; to pay for their care, people often are forced to relocate or to mortgage their homes.
- Recently, the IHS in Montana has recognized the need to support cancer care for Native Americans and has been both paying for and helping to facilitate access to this care. Arrangements to provide cancer care through emergency rooms have been established at two reservations.

- At the national level, the ACS actively engages cancer patients in the political process, but similar State-level or grassroots efforts have been limited. In addition, Montana has only one U.S. Representative, so its influence on national politics and policy is limited. Montana is not the only State in this situation, and the voices of those outside the major metropolitan areas need to be heard.
- Many of the uninsured in Montana avoid cancer screening or care because they know that once treatment is initiated, a cascade of events will occur that is likely to end in family bankruptcy. People need to know there is a system in place that will enable them to obtain care without the threat of financial disaster. This problem would be resolved by a system of universal access to care.

## **Recommendations**

- Medicaid eligibility criteria should be relaxed for cancer patients. Currently, Medicaid considers the patient's home an asset, even if it is mortgaged. Eligibility determination under the Children's Health Insurance Program (CHIP) does not include such an asset test. Medicaid should use CHIP as a model and remove home ownership from the asset test to enable cancer patients to receive Medicaid-financed care without having to lose their homes.

## **STATE OF SOUTH DAKOTA**

### **Presenters:**

**Ms. Karen Johnson-Pochardt**

**Ms. Cathey Ducheneaux**

**Mr. Walter Woods**

**Ms. Arliss Keckler**

**Ms. Dolly Randles**

**Ms. Pat Myers**

### **MS. KAREN JOHNSON-POCHARDT**

#### **Background**

South Dakota is a large State with a population of approximately 650,000 people. It is over 400 miles from east to west and over 200 miles from north to south. The two major population centers are separated by 350 miles of Interstate. Rapid City, in the western portion of the State, has a population of approximately 80,000 people. Sioux Falls, in the southeast, has a population of approximately 120,000. More than two-thirds of the State's population reside outside these two population centers.

Six cancer programs in South Dakota are approved by the American College of Surgeons; a seventh program is emerging but is not yet approved. The six approved programs are located in Rapid City, Aberdeen, Watertown, Yankton, and Sioux Falls (two programs). The newest program will be located in Mitchell. South Dakota is divided between the East and West River regions. South Dakota is bisected by the Missouri River, and residents commonly refer to themselves as hailing from either East or West River. There are nine federally recognized Indian tribes in South Dakota.

Of the seven Cancer Centers in the State, those located in Sioux Falls and Rapid City are NCI research affiliates, working closely with the North Central Cancer Treatment Group at the Mayo Clinic as well as with several other NCI-designated clinical trials groups. Pharmaceutical studies also are performed at

Sioux Falls and Rapid City. No access to clinical trials exists, however, outside these two major population centers.

## **Key Points**

- Cancer is not merely a physical disease. It affects people on physical, emotional, social, spiritual, and economic levels. When cancer is diagnosed, the importance of close support of family and friends cannot be overemphasized. The role and importance of the extended family in Native American culture is of particular significance in South Dakota.
- Optimal treatment for all patients is to provide treatment as close to home as possible, including inside the home. Although some types of cancer care, such as radiation therapy and other treatments involving high technology, cannot be provided at home, access to other treatments at home is possible, such as administration of Neupogen.
- The Rapid City Regional Hospital Cancer Institute uses a full-time case manager to identify patients requiring extra care throughout the cancer system. For example, some patients may require special assistance in navigating a complex array of third-party payers to coordinate service delivery and reimbursement. Increasing financial constraints are making it difficult to retain this staff position.
- The National Cancer Policy Board (NCPB) has defined optimal cancer care from the patient's perspective to include: access to comprehensive and coordinated services; confidence in the training and experience of providers; provider respect and advocacy; full participation in decisionmaking; clear understanding of the disease and diagnosis; awareness of treatment options, including risks and benefits; confidence in treatment appropriateness and effectiveness; congruence between personal preferences and treatment approaches; prospective planning for treatment and palliation; professional coordination of treatment plans; and assurance that treatments comply with national quality standards.
- The NCPB also has defined an ideal cancer system as one that: implements policies to achieve goals consistent with quality care; coordinates diverse systems of care; ensures appropriate cancer provider training; facilitates translation of research into clinical practice; and conducts research to improve cancer care effectiveness.
- As in Montana, primary care physicians in South Dakota are providing oncology care; this is an issue of considerable concern.
- The availability and cost of transportation to and from the two principal population centers present barriers to obtaining cancer treatment and supportive care services. Air travel to Rapid City and other South Dakota destinations is particularly expensive because the volume of traffic is low. Other barriers to treatment include: limited public transportation; poor roads; lack of telephone service (particularly on the reservations); challenges associated with coordinating multiple managed care systems (e.g., Medicaid, Medicare, U.S. Public Health Service, IHS, VA, TriCare, and private insurers); cultural diversity; and the financial burden of unreimbursed medically related expenses. Expenses that most rapidly bankrupt people with cancer are nonmedical expenses and the temporary or permanent loss of income that may follow a cancer diagnosis.
- Only three of the seven cancer treatment centers engage in clinical trial research and cutting-edge radiation oncology. These treatment centers are geographically inaccessible for most South Dakotans. Harsh weather conditions further compound the access problem. South

Dakota roads are impassable at least three to four times each year, often resulting in interrupted treatment cycles and lack of compliance.

- Distance from cancer care contributes to the rapid depletion of family savings used to pay for transportation, food, and lodging. These costs are in addition to out-of-pocket expenses such as deductibles and copayments. If, every day, a half-day of travel is required to obtain even brief cancer treatment, little time or energy remains for earning income. In addition, South Dakota has a high poverty level.
- Access to home health and hospice services is limited. For example, in the West River region, there are three hospice providers serving a 200 by 200-mile area.
- When the distance to treatment is great, some patients decline treatment or select more extensive surgery to avoid the need for daily radiation. Family members often must make hard choices between caregiving and income-producing responsibilities. Similarly, patients often choose a less attractive treatment option because it is less devastating financially and/or will allow them to return to work more quickly. It is not unusual for a ranch wife in western South Dakota to choose mastectomy over lumpectomy with radiation, and to forego reconstruction, in order to return to her ranch and family duties more quickly.

## **MS. CATHEY DUCHENEAUX**

### **Background**

The Rapid City Regional Hospital Cancer Institute provides care to residents of the West River area, which includes three Native American reservations. In Rapid City, there also is one Native American hospital.

### **Key Points**

- Clinical data for the last 2 years at Rapid City Regional Hospital indicate that 86 of the 196 patients from the reservations had to drive more than 3 hours to receive care. Travel difficulties (e.g., inability to obtain gasoline) frequently cause interruptions of up to 2 months in patients' treatment regimens. Patients also have surgery outside the immediate area or out of state and then return home with a need to continue care. Information lags between the IHS and providers make it difficult to locate patients and provide local followup care; this situation also causes treatment delays that jeopardize the patient's outcome.
- It is particularly difficult to convince patients of the need for additional and extensive care when they are asymptomatic or pain-free and care is geographically inaccessible. Some patients travel great distances to reach Rapid City and must remain in treatment for as long as 6 months. This results in lengthy absences from home and a need for local housing, which is not provided by the IHS. Housing assistance has been provided by the Native American Heritage Association; however, the demand exceeds the supply. Patients on fixed incomes typically do not have sufficient funds to support them while they are receiving treatment out of town. Limited stipends of \$20 per week are available, but this amount is grossly insufficient to meet the patients' needs. No additional support is available for a family member or other person who accompanies the patient to treatment.
- Weather conditions in winter are quite severe; patients may leave the treatment site for the weekend to return to their families, only to find the roads impassable when it is time to return.

- Many Native American patients are unaware of the variety of Federal programs that provide funding for health care. Typically, patients expect that their care will be fully funded by IHS and do not understand that other programs, such as Medicare and Medicaid, may also finance their care. This confusion sometimes results in anger and frustration that may cause patients to discontinue treatment or may result in treatment delays.
- Because of travel costs and long waits for care at overcrowded facilities, Native Americans often resist seeking any type of health care until they are symptomatic. Cancer is therefore most often detected during acute episodes rather than through screening. Newly diagnosed patients may be suspicious of provider motives regarding the need for additional testing and believe that testing is suggested merely to increase provider income. Upon diagnosis, Native Americans frequently wish to consult their medicine men to provide spiritual support and counsel. Medicine men are sometimes brought into a treatment facility to provide support, and patients can participate in special ceremonies associated with their disease and recovery, either at home or in the facility. By including traditional healers in the patient's care, the likelihood is greater that the patient will accept the recommended mainstream cancer treatment.

## **MR. WALTER WOODS**

### **Background**

Mr. Woods, who is 76 years old, resides in Eagle Butte, South Dakota, a part of the Cheyenne River Indian reservation. He is a retired judge and a World War II, Korean War, and Vietnam veteran.

Mr. Woods also is a 5-year survivor of prostate cancer. When he suspected he had a health problem, he went to the nearest VA facility, where he was examined by both a urologist and an oncologist. At the time, he knew little about prostate cancer. He was advised to receive 8 weeks of radiation therapy, but he would have declined the treatment had not IHS agreed to provide housing for him at a lodge at the Sioux San Hospital, a 3-hour drive from his home.

### **Key Points**

- Cancer screening programs should be available on the reservations.
- Data on prostate cancer among Native Americans living on reservations are nonexistent. A single oncologist and a single urologist provide cancer care to all of the reservations in South Dakota; the oncologist indicated that Native Americans have the lowest incidence of prostate cancer, yet the highest prostate cancer death rate. More generally, cancer-related data for Native Americans are lacking. Such data should be more accessible from the IHS, since it is currently unavailable from other sources.
- Mr. Woods approaches men individually to urge them to get prostate cancer screening. However, none of the staff at the IHS facilities is knowledgeable about prostate cancer, and the tendency is to refer patients elsewhere.
- Efforts must be made to educate Native Americans about cancer using a variety of media, such as pamphlets, videos, and group presentations. Mr. Woods conducts cancer education programs on the reservations; these tend to draw small groups of people, comprising mostly women. Women are more willing to discuss health issues openly. Support groups should also be available to cancer patients and their families.

- Mr. Woods questioned whether we are winning the war against cancer; despite increasing research and expenditures on cancer, there appears to be little progress. Native Americans return to their traditional healing when confronted with cancer because they have little confidence in mainstream medicine.

## **MS. ARLISS KECKLER**

### **Background**

Ms. Keckler is a member and former administrator of the Cheyenne Sioux River Tribe in Eagle Butte, South Dakota.

### **Key Points**

- The IHS does not adequately meet the health care needs of Native Americans. Moreover, IHS makes sure that it is the payer of last resort. Native Americans with no other source of insurance are limited to IHS' participating providers. Costs associated with second opinions are not covered by IHS, so Native Americans generally do not obtain those opinions. They accept the care that is available and try to make the best of it, often not understanding what cancer is and believing that death from cancer is inevitable.
- Education about the value of prevention and early detection is essential. The tribes obtained direct funding from the CDC to establish their own 5-year program for breast and cervical cancer. One of the major factors leading the tribes to seek independent funding was to have control of decisionmaking regarding program elements and to ensure that information would be provided in a culturally relevant and appropriate manner. When the program was established, a Lakota-speaking community liaison was hired to generate program support and to establish trust. Though the program is growing, there still are educational issues to be addressed—for example, women believe that Pap smears are no longer needed if they have had a hysterectomy.
- The tribe experiences some of the same problems identified by earlier speakers, including lack of transportation, nonreimbursable childcare costs, and lack of funding to enable family members to accompany patients when they receive care.
- The tribes take care of critical needs, but to do so, funds must be diverted from equally important initiatives. The tribes are underfunded—the Indian Health Service is funded at 59 percent of need. Consequently, social needs related to cancer treatment are not addressed. Native Americans focus first on their ability to meet daily living needs, such as food and transportation. Disease screening in the absence of symptoms, especially in the absence of pain, is not a priority.
- Adequate housing is essential to attract and retain medical providers and currently is lacking. Continuity of care is a key element in gaining patient trust and in providing quality care; this, too, is a shortcoming of the current system, in which providers are only in the area for brief periods and seldom get to know the patients. There is a particular need for female providers.
- Mammograms and Pap smears are provided on the same days to avoid the need for multiple clinic visits. Because many patients have traveled from distant parts of the reservation and have nowhere to go at noon and little money, lunch is provided by the program. Patients often have to wait a long time for transportation back to their homes. The clinic provides limited transportation but is unable to meet demand due to lack of funding.

## **MS. DOLLY RANDLES**

### **Background**

Ms. Randles is from Rapid City, South Dakota. She has survived cancer for over 40 years. Many of Ms. Randles' family members have died from cancer, including a grandmother with stomach cancer, her father with lung cancer, one sister with brain cancer and another with breast cancer, and a 42-year-old daughter with metastatic adenoid cystic carcinoma. To illustrate the difficulties Native Americans face in obtaining quality cancer care, Ms. Randles recounted the diagnostic and treatment experiences of two cancer patients.

### **Key Points**

- Ms. Randles' daughter was diagnosed with adenoid cystic carcinoma, a rare cancer, and was referred to Portland, Oregon, for surgery due to a lack of qualified providers in Rapid City. To pay for her travel expenses, several fundraisers were held over a period of 5 months. Following surgery, she was told that had she received surgery 4 months earlier, she could have been cancer-free, but because treatment was delayed, she would only live 1 year. She returned home to recuperate. When her health again declined, she was referred to the Mayo Clinic. Because the Mayo Clinic had virtually no experience in treating adenoid cystic carcinoma (they previously had seen only one case), she was referred to Seattle, Washington, for a neutron beam treatment, reported to be 100 percent more powerful than radiation. Again, fundraisers were held to finance her travel. Her 6-week treatment regimen expanded to 6 months, requiring that she and her husband find temporary housing near the facility at a cost of \$1,400 per month. She died after a painful 6-year struggle with her disease, leaving her husband with more than \$100,000 in treatment-related debts. He is working three jobs to repay the debt and feels a strong obligation to avoid declaring bankruptcy because his wife received the best possible care.
- Ms. Randles reviewed the case of a 66-year-old man diagnosed with prostate cancer in April 1991. He received all of his treatment at the closest major cancer facility—in Rapid City, South Dakota, 150 miles from his home. The recommended treatment regimen included 35 radiation treatments followed by 3-month followup appointments during the first year. In 1999, his cancer recurred in his spine, requiring four rounds of radiation consisting of 10 to 14 days per round. Considerable out-of-pocket costs were incurred, including gasoline (\$34 per trip), meals, and medication for pain and infection prevention. A 30-day supply of another recommended medication with the potential to slow the progression of his disease costs \$353 per month; since it is an oral medication, it is not covered by Medicare. These expenses have been overwhelming, since the patient and his wife live on a fixed monthly income of \$1,064.

## **MS. PAT MYERS**

### **Background**

Ms. Myers is from Rapid City, South Dakota, and is a cancer survivor. Because of her disability status and low income, her cancer treatment is financed fully by Medicaid and Medicare. She is fortunate to live within 5 miles of the nearest cancer treatment facility and has her own transportation. She indicated that if she were not covered by both Medicare and Medicaid, she would be forced to forego any treatment because it would be unaffordable. Ms. Myers lives on \$495 per month, has no other sources of income, and is unable to work because of her disease.

## **Key Points**

- Ms. Myers first saw a doctor a year ago, complaining of night sweats. She was told there could be many causes, and to wait to see if other symptoms developed. Months later, she awoke in pain and underwent emergency surgery; the mass that was removed proved to be malignant. She then experienced a torturous 3-week delay in learning the results of her tests and obtaining an appointment with an oncologist to develop a followup treatment plan.
- Accompanied by a fellow cancer survivor who helped her ask questions and gather information, Ms. Myers met with a radiation oncologist to discuss treatment options and emerging technologies such as brachytherapy. She found that most physicians in the area tend to rely on traditional treatment approaches and are not always open to trying new therapies.
- Low-income individuals have insufficient access to current information about cancer. They do not own computers, nor could they afford Internet access fees if they did. The poor have few resources for conducting their own research into their disease and treatment alternatives. Medical facilities focus on treatment and provide little information concerning cancer prevention. People with low incomes often do not take the initiative to seek out information regarding their disease because they feel inadequate. Programs for specific minorities, such as the IHS, reach some low-income individuals; however, it is Ms. Myers' observation that similar programs do not exist for the white population—at least, not in Rapid City.

## **DISCUSSION—STATE OF SOUTH DAKOTA**

### **Key Points**

- Currently, South Dakota has no State Cancer Registry, but the State did request CDC funding for a population-based registry within the last 6 months (it was the last State to do so). An obstacle to implementing the registry is the CDC requirement that cancer become a reportable disease (i.e., that cancer case reporting be mandatory). In South Dakota, residents resist rules of all kinds. For example, helmets are not mandated for motorcyclists, and seat belts are not mandated for automobile drivers and passengers. Although this attitude may pose some difficulty in developing the registry, the State is moving forward with the registry and plans to adhere to the reporting requirement.
- Federal program guidelines indicate that if a patient has private insurance, the commercial insurer is responsible for the health care costs covered within the patient's commercial plan. If no commercial coverage is available, or if certain costs are not covered under the commercial plan, Medicare or Medicaid becomes responsible if the patient is determined to be eligible under program guidelines. Patients must receive care from approved providers or facilities to obtain reimbursement. To receive IHS health care coverage, one must live on a reservation. People living on the reservations can be covered by Medicaid, but they must make application. The Rapid City Regional Hospital Cancer Institute retains an outside firm to assist patients in obtaining Medicare or Medicaid coverage. The IHS typically is the payer of last resort.
- If patients receive prescription drugs from a provider they sought out on their own, the patient is financially responsible for the cost of the medications. IHS will not cover the medication cost because it did not make the referral to the provider.
- People tend to seek care from the IHS facility only when they are very sick. The facility waiting time is lengthy—as much as 3 to 4 hours—and transportation to facilities is difficult.

Consequently, patients do not seek care until their situation is urgent, because they know that emergency care will be provided immediately.

- Third-party insurers, particularly Federal health care programs such as Medicare, Medicaid, VA, and IHS, continually shift patients from one program to another to avoid responsibility for reimbursement. Patients are typically unaware of which payer is responsible at any given time and often assume responsibility for copayments that might have been avoided if the correct program had been billed.
- Similarly, Rapid City Regional Hospital Cancer Institute experiences a 38.6 percent bad debt ratio with VA patients. This situation often arises because the VA encourages veterans to identify Medicare as their primary payer, but patients are not made aware that unless they have coverage under Medicare Part B, all of their outpatient services must be paid out-of-pocket. Since they cannot afford to pay the bills, they often simply ignore them, and the hospital is forced to absorb the costs.
- Because of cultural and language barriers, Native Americans may give providers incomplete descriptions of their health care issues and may be prescribed inappropriate or ineffective treatment or medications. After a period of time, when the prescribed treatment does not resolve the health problem, the patient must return to the IHS facility and again wait all day to be seen. Each time, the patient sees a different physician, since virtually all of the providers at IHS facilities are transient.
- Physician turnover at IHS facilities is exceptionally high, in part, because of the extremely high patient load, low reimbursements, and the remote locations of many of the facilities. In some facilities, the situation is so severe that it is impossible to provide primary care. In Rapid City, many physicians are refusing to take new Medicaid and Medicare patients because of low reimbursement levels.
- National attention must be focused on the need to disseminate cancer education to Native Americans. There must be a commitment at the highest levels to ensure that sufficient staff and funding are available for public education at the local level.
- A participant identified the existence of an NCI-funded program at the Mayo Clinic, the Native American Cancer Information Resource Center and Learning Exchange, also referred to as Native C.I.R.C.L.E. Native C.I.R.C.L.E. collects brochures, cookbooks, and other Native American-specific educational material from groups across the country and disseminates them to anyone who requests them. Native C.I.R.C.L.E. covers the cost of reproducing and distributing the materials.

## **WYOMING**

### **Presenters:**

**Dr. Karl Musgrave**

**Mr. Chris Lorenzen**

**Ms. Dawn Howerton**

**Ms. Margaret Parry**

**Dr. Charles Tweedy**

**Ms. Lisa Eades**

### **DR. KARL MUSGRAVE**

#### **Key Points**

- Wyoming has had a Cancer Registry since 1962. It collects more than 80 different data elements from hospitals and physicians. This information is entered into a Health Department central database and also is included in a regional cancer database. Registry data have been used to study populations that lack good access to care and to identify access barriers. One such study focused on whether women who received breast-conserving surgery received radiation therapy after surgery. A direct correlation was found between the distance to the radiation treatment center and whether the patient received treatment. This information was published in *Cancer Chronicles*, a Health Department-sponsored newsletter distributed to all physicians and hospital administrators in the State. The Registry also serves as an information source for the general public and legislators.
- Cancer registries can raise awareness of health care access problems and their impact on health status. For example, using Registry data, the Health Department performed a study of breast and cervical cancer deaths. The study examined disease stage at diagnosis by health care shortage area. No association was found between residence in a health care shortage area and late stage at diagnosis. When the study results were published by the Associated Press, legislators received inquiries from constituents for more information and were themselves made more aware of the issue.
- Registries also can provide county-specific data that focus on local cancer issues, including possible environmental exposures, and provide the basis for local programming and community education efforts to address them.
- Registry data can provide the impetus for community collaboration and can be used to support the activities of relevant advocacy groups and form the foundation for collective action.
- One of the barriers to developing a good cancer registry is the difficulty hospitals experience in reporting data to the State. Hospitals are trying to survive, and they face pressures to contain costs. Personnel costs associated with registry maintenance are not a top priority when compared with maintaining other key positions. Additionally, although CDC supports State registries, States must supply a three-to-one funding match; in some cases, State legislators are unwilling to appropriate these funds.

## **MR. CHRIS LORENZEN**

### **Key Points**

- In Wyoming, the population aged 45 to 64 is expected to increase 28.45 percent over the next 5 years. Since cancer rates increase dramatically as the population ages, concern about the ability to provide quality cancer care is rising. A major issue in Wyoming is the extent to which patients leave the State for care. In a few counties, especially at the State borders, there is an out-migration for care of nearly 85 percent, resulting in a loss of funds that could help support local care.
- In small Wyoming communities, if a surgeon is present, surgery tends to be the predominant treatment option. Physicians in these communities also administer chemotherapy, even though they do not have the requisite experience and training. To help address this problem, the Wyoming Cancer Center assigned a nurse to train providers to a minimal (though, admittedly, probably still inadequate) competency level determined by the Oncology Nursing Society (ONS).
- Though many areas of Wyoming are considered to have reasonable access to radiation treatment facilities, some patients must travel in a WCC van—300 miles daily, for up to 6 weeks—to receive radiation treatment. To remedy the geographic barriers to care, the Medical Center spends approximately \$500,000 to \$1 million annually to fly an oncologist to outreach clinics to see patients in remote locations. In a day, the oncologist may travel 800 miles and see 13 to 20 patients.
- Areas in the State considered to lack reasonable access to care have alarmingly low service usage rates compared with reasonable access areas. For example, 25.3 percent of those living within 150 miles of a treatment facility received radiation for prostate cancer, compared with 9.7 percent of patients in areas with less access. Radiation treatment for breast cancer was provided to 41.3 percent of patients in reasonable access areas, but to only 11.8 percent of patients in areas with more limited access.
- Nationwide, 75 percent of women with breast cancer receive a surgical biopsy of some type; of these, three-quarters received stereotactic breast biopsies. In Wyoming, only one or two hospitals have the facilities to perform this procedure.
- The Wyoming Cancer Surveillance Program experiences difficulty capturing complete cancer-related data because many patients seek cancer care outside the State, and a great deal of care is provided in physicians' offices, where data are difficult to access.
- Only 2 percent of Wyoming's population is enrolled in managed care programs. Medicare is the predominant payer, comprising 56 percent of the payer mix in the State; therefore, decreases in Medicare reimbursement have a profound negative impact in Wyoming.

## **MS. DAWN HOWERTON**

### **Background**

The Breast and Cervical Cancer Early Detection Program at the Wyoming Department of Health in Cheyenne is a CDC-funded program designed to serve women with limited income who are either uninsured or, if insured, do not receive reimbursement for cancer screening. Program guidelines stipulate that 75 percent of enrollees must be between the ages of 50 to 64; however, the State also is permitted to

enroll women aged 40 to 49 who have a family history of breast cancer. Enrollment can also include women of any age with breast cancer symptoms. Services include pelvic exams, Pap tests, clinical breast exams, mammograms, and limited diagnostic testing. The Wyoming affiliate of the Susan G. Komen Foundation provides limited breast cancer treatment funding for five women (up to \$8,500 per woman). However, similar funding for cervical cancer treatment is unavailable. Limited treatment funding is a deterrent to provider participation in the program, since providers must write off nonreimbursed costs.

Women in Wyoming also can take advantage of a national grant from the Avon Foundation to Cancer Care, Inc., in New York. The grant provides limited funding to underinsured low-income women for diagnostic services and/or treatment; limited funding also is available for transportation costs. The Wyoming Breast and Cervical Cancer Detection Program works with Cancer Care to arrange this funding for Wyoming women in need.

### **Key Points**

- Wyoming lacks adequate numbers of health care providers and radiology facilities. Medicare reimbursement rates are insufficient to retain providers, and the State is unable to provide funding for breast, cervical, and ovarian cancer treatment.
- Approximately 16 percent of Wyoming residents lack health insurance, and 10 percent of households earn less than \$10,000 per year. State breast cancer incidence and mortality data reveal that women living in counties with a health care provider shortage typically are diagnosed at later stages and have higher breast cancer mortality rates than women in non-shortage areas. Forty percent of the counties in Wyoming are considered health care shortage areas.
- In 22 percent of Wyoming counties, a woman must leave her area of residence to obtain a mammogram if she is enrolled in the Breast and Cervical Cancer Early Detection Program. A mobile van based in Rapid City travels through the western counties once a year to provide mammograms to women in remote areas. Another van, based in Utah, also serves these areas but did not come to Wyoming this year because it needed repair and because the sponsoring program in Utah was being reorganized. As a result, women who relied on that mobile unit did not receive their annual mammograms.
- Women in Wyoming often do not receive mammograms because they do not understand the need for preventive health care when they are symptom-free and are afraid to find out that they might actually have cancer. The prevailing attitude is that one does not go to the doctor unless something is wrong. In addition, Wyoming does not require insurance companies to provide reimbursement for mammograms and Pap tests as part of their standard benefit packages, creating a financial barrier to early detection preventive services. Moreover, no State funding is available to cover treatment if cancer is diagnosed.
- Screening guidelines are confusing to women because even the experts disagree about the age at which mammography should begin and the intervals at which the test should be performed.
- Wyoming has only two cancer treatment centers, located in Casper and in Cody. Travel to these centers or outside the State for cancer care may be impossible for low-income patients, who may not have either sufficient funds or a vehicle necessary to make the trip.

### **Recommendation**

- All counties should consider providing free or low-cost mammograms and Pap tests to women who have low incomes and are uninsured or underinsured. People should not have to choose between basic needs and cancer treatment. Further, funding should be provided to

market existing programs such as the Wyoming Breast and Cervical Cancer Early Detection Program or perhaps to design, install, and maintain software that residents could access via a toll-free telephone number to determine their eligibility for various health care programs.

## **MS. MARGARET PARRY**

### **Background**

Ms. Parry, a breast cancer survivor, is the founder of Cowboys Against Cancer ([www.cowboysagainstcancer.com](http://www.cowboysagainstcancer.com)), a nonprofit organization located in Green River, Wyoming. Cowboys Against Cancer provides funding for cancer patients who must travel out of town to receive treatment. The organization provides \$500 per patient to use in any way they see fit to relieve the financial burden of cancer treatment. Funds typically are used to pay for hotel rooms, transportation, food, and childcare. The combined efforts of volunteer fundraisers have made it possible to provide more than \$100,000 to local cancer patients. Over the past 5 years, more than 200 people have been helped. The ultimate goal of the program is to establish a cancer treatment center in Sweetwater County, Ms. Parry's home county, to enable patients to remain at home with friends and families while they receive cancer treatment.

### **Key Points**

- Due to the lack of cancer treatment facilities in southwest Wyoming, Ms. Parry had to travel 3 hours to Salt Lake City, Utah, for her breast cancer treatment, which required a 6-week stay to complete radiation treatment and biweekly travel for 9 months thereafter to receive chemotherapy. At the time of her diagnosis, she was adequately insured and married to a medical professional, who facilitated her access to cancer-related information through professional networking. There were, however, virtually no formal programs available to provide information and support. Since diagnosis, her situation has changed dramatically. She is no longer married, and her insurance benefits have been greatly reduced. Under her current plan, not even mammograms are a covered benefit.
- In Sweetwater County, most residents are insured through their employment in the mining industry. Cancer patients in the area are concerned with locating a treatment facility and a doctor who can provide the most up-to-date care.
- As an advocate for breast cancer awareness, Ms. Parry has spoken to more than 6,000 people in the Intermountain area. She emphasizes the need to take responsibility for one's health and the importance of performing monthly breast examinations. Her goal is to promote the earliest possible detection of breast cancer, thereby limiting the amount of disfiguring and painful surgery, family suffering, medical expense, and, most importantly, the number of breast cancer deaths. She maintains a Web site at: [www.margaretparrypresents.com](http://www.margaretparrypresents.com).

## **DR. CHARLES TWEEDY**

### **Key Points**

- Dr. Tweedy previously held faculty appointments at a number of major universities. While in the academic environment, he and his colleagues believed that it was only in the academic setting that the best cancer care was provided. Now, from his vantage point as the director of a community cancer treatment program, Dr. Tweedy recognizes the quality of the care being delivered at the community level—as well as the unmet needs. He also recognizes that this

difference in perspective between the academic and community environments constitutes an important aspect of the disconnect between discovery and delivery.

- In rural settings, the unserved and underserved population is the *entire* population because there are too few providers, particularly specialty care providers. This lack of access to qualified cancer care physicians is one of the most significant barriers to quality cancer care. To receive cancer treatment, patients must travel great distances from their homes, often under severe weather conditions. Many facilities also lack sufficient technology—such as computer tomography (CT), magnetic resonance imaging (MRI), positron emission tomography (PET), mammography—as well as adequate pathology and laboratory services to support diagnosis and treatment. In many cases, chemotherapy is being administered by family practitioners, surgeons, or other providers lacking the appropriate training to provide this care.
- Because uninsured patients generally do not go to physicians, they are less likely to receive a screening mammogram, Pap smear, or other early detection service. In his practice, Dr. Tweedy ensures that once a person enters his office, needed care will be provided regardless of ability to pay. For example, needed chemotherapy medications can be secured through donations from the pharmaceutical companies.
- A great deal of misinformation exists in the community regarding cancer screening and treatment approaches. Women believe that mammograms are painful and that surgical procedures are directly responsible for cancer metastasis. These misperceptions deter patients from seeking necessary services until they have advanced disease, for which there are fewer treatment options. Efforts are needed to persuade patients to come for care when they first recognize a problem so that diagnosis can be made early, when the possibility of cure is greatest.
- There is no consensus as to what is meant by *state-of-the-art*, *Cancer Center*, and *quality care*. It also is important to define what is considered to be a “worthwhile” outcome of a particular intervention; how such definitions should be reached (e.g., based on what data); and by whom these definitions should be developed (e.g., physicians, patients, payers, others).
- The scientific and medical communities must do a better job of presenting data on treatment options. These data often are conflicting and do not clearly indicate preferred treatment approaches. In addition, media reporting on cancer treatment options and advances has often been irresponsible. In both the scientific community and the media, there is a clear bias to present positive rather than negative data. Patients assume that a reported treatment is state-of-the-art care, and the physician must be extremely careful in interpreting media information for the patient. Moreover, inappropriate fiscal incentives may cause one treatment to be promoted over another. National Comprehensive Cancer Network (NCCN) guidelines are helpful for physicians who lack access to major university programs. Consensus statements should be developed on the standard of care for specific diseases based on the best available data; these statements should stand until new data clearly indicate that another treatment approach is more effective.
- Reducing the amount of time physicians must spend on administrative duties associated with health care delivery will result in increased access to care for patients. Physicians and their staffs spend countless hours dealing with insurers, attempting to process claims, define needed treatments, and advocate on behalf of patients.

- Implementing proposed Medicare ambulatory payment classifications (APCs) will essentially put an end to cancer care. Under the proposed mechanism, providers would be reimbursed for older, less effective therapies but not for current technology. The APCs are a direct contradiction of the Government's stated desire to improve cancer care.
- Both physicians and the public must be educated to advocate for and demand appropriate health care.

## **MS. LISA EADES**

### **Background**

Ms. Eades is Vice President of the Jason's Friends Foundation in Casper, Wyoming. At age 8, her son, Jason, was diagnosed with a brain stem tumor. The family was told to travel immediately to Denver Children's Hospital, a 5-hour trip, where physicians indicated that with chemotherapy and radiation, Jason might survive a year. Returning to Wyoming, the family conducted extensive research about the disease and other treatment possibilities, finally traveling to New York University to seek treatment for Jason. For the next 11 months, he was in and out of treatment, which included surgery, radiation, chemotherapy, and physical, occupational, speech, and swallow therapy. The family lived in New York for much of this time, also frequently traveling back and forth to Wyoming. Both parents left full-time jobs and a 4-year-old daughter in Wyoming in order to concentrate on Jason's care. The drain on the family, and emotional reserves was extreme. In November 1995, Jason succumbed to his disease.

Following Jason's death, the Foundation was established by community members who had witnessed the many financial, physical, and emotional challenges Ms. Eades' family had experienced. Its mission is to assist families of pediatric cancer patients throughout Wyoming. The Foundation is an all-volunteer, nonprofit, 501(c)(3) organization. Ninety-eight percent of funds received by the Foundation are disbursed directly to needy families. The Foundation provides financial assistance for nonmedical costs, provides emotional support, and assists with information-gathering to enhance family and provider communication regarding the child's disease and care. Typically, support provided by the Foundation is used to cover travel expenses, rent payments, utility payments, vehicle maintenance, food, and clothing. Payments to individual families may range from several thousand to over \$30,000. An underlying principle of the Foundation is that a family should not have to become destitute simply because it has a child with cancer.

### **Key Points**

- The lack of primary cancer treatment for children in Wyoming requires that a family travel out of state with its sick child to receive care. This results in immediate family disruption, and siblings are often placed in the care of extended family or friends to enable the parents to focus on the needs of the sick child. Most often, one or both parents must leave a job to travel to treatment sites in Denver, Salt Lake City, or other distant locations. The family income is quickly halved or worse, inflicting significant financial hardship in the midst of an already difficult time.
- For example, some families living in Gillette, Wyoming, must regularly travel with their sick children to Denver for treatment—a 12-hour trip of over 700 miles. One family has endured this hardship for over 3 years and logged more than 110,000 miles on the road. They have endured treacherous road conditions, been stuck with a sick child in the car in adverse weather conditions, and lost both an extensive amount of time from work and family income. On returning to Wyoming, these families receive care from local physicians and nurses who

are not sufficiently trained to provide pediatric cancer care. For example, in Casper, Wyoming, one of the two largest cities in the State, a general pediatrician provides chemotherapy to children.

- Blood transfusions and platelets for children also are difficult to obtain in Wyoming. Families living in Rock Springs (the fifth largest community in Wyoming) must travel 4 hours to receive necessary services.
- Parents of a child with cancer are made to feel a tremendous sense of urgency to begin treatment following diagnosis, and to fear that their child will die if treatment is not initiated immediately. They do not believe they can afford the time to research alternatives and tend to select the most readily available physician and treatment protocol, whether or not it is the best available for their child's illness. This problem is further compounded by insufficient access to cancer-related information and computer technology, and by low educational levels that may make it difficult, if not impossible, for the parents to find and evaluate relevant information. With a limited understanding of the diagnosis, families are unable to ask the most pertinent questions of providers.
- Lack of finances may pose the greatest obstacle to locating and accessing specialists. It is expensive to make long-distance phone calls, to duplicate and mail medical records and test results, and to travel great distances on short notice to meet with providers. Travel often includes overnight stays that add to the financial burden.
- Financial difficulties are further compounded because specialists frequently require payment from patients at the time service is rendered, often at much higher rates than are covered by insurance. In addition, since parents of the sick child often lose their jobs due to extended absences, they lose the family's health insurance benefits. When they then seek medical assistance, they are told they have too many assets (in one case, the family car needed to drive the 700 miles to and from Denver for treatment) to qualify for the program.
- In so many cases, the children with cancer who get the best treatment are those whose families have money and education. Many bereaved parents are left to wonder if their child would still be alive if only they had had access to better care.

## **DISCUSSION—STATE OF WYOMING**

### **Key Points**

- The Internet holds a great deal of promise for improving relationships and communication among geographically scattered providers, but a lack of digital line access in some communities has hampered activation of an Internet-based Tumor Board. Through a National Library of Medicine grant, 66 sites in Wyoming will gain access to digital lines and participate in the Internet Tumor Board.
- The outreach clinic system in central Wyoming has decreased out-of-state travel for cancer treatment. Full chemotherapy services are available, and nurses and physicians are flown to the area weekly; this arrangement has improved access and the relationship between providers and patients as they navigate the health care system, but it still addresses only 40 to 50 percent of community need.
- Seeking Government-funded solutions for all health care system problems is not the best approach. It is better to establish effective programs locally, and then request Government support. Too often, communities or programs request assistance before they have a proven

track record and then find they are unable to provide the services for which funding has been requested. Partnerships, particularly with universities, are especially important in designing effective programs and enhancing service delivery.

- Providers need to do a better job of taking state-of-the-art medicine out to the local communities. There will be some services and types of care that cannot be provided locally; however, arrangements can be put in place to make these services more readily available in other areas (e.g., partnerships, transportation assistance). Moreover, providers cannot wait for patients to come to them, but must actively engage in outreach efforts to bring patients to the health care system.
- Cancer is not sufficiently recognized as a chronic rather than an acute illness that has a long-term impact on family employment, family functioning, and many other areas. All of these needs of the patient and family must be met. Local health systems and communities should attempt to find solutions to meeting these needs, but governmental assistance may be required.
- Clinical trial access in Wyoming has been extremely limited. Recently, however, 5 international research trials have been opened, and there are plans to open 15 to 20 additional trials. Participation in clinical trials will increase as more trials become available locally. Physicians still are extremely reluctant to hire data managers and to comply with all of the administrative demands accompanying clinical trial participation, yet provider commitment is critical to conducting trials at the community level. Currently, only 3 percent of adults with cancer participate in clinical trials; increased participation is needed to clearly answer questions concerning the best approaches to cancer treatment.
- As important as clinical trials may be, it is more important to ensure that all people with cancer receive at least accepted standard care across the continuum of care, including early detection.
- To develop Centers of Excellence in small communities, provider competition will have to be replaced by a commitment to delivery of coordinated, quality cancer care. A team approach to care delivery would help ensure greater access to care in distant locations and help to avoid duplication of resources.
- Although competition is inherent in the U.S. health care system as a whole, for the good of the Nation, providers must recognize that they cannot be all things to all people. However, provider competition in the western U.S. is less of a problem than in the East. Unlike the issues prevalent in eastern and some Midwestern urban centers, where duplication of services and technologies creates competition, in many parts of the West, issues of providing basic resources to support care delivery are most pressing.
- Every NCCN-participating institution should be partnered with communities so that therapies and clinical trials are more accessible locally. Such partnerships could be established on a regional basis, with groups of communities assigned to the most appropriate institutions. Under such an arrangement, however, the local facilities must be able to maintain their operational and fiscal autonomy.

## **IDAHO**

### **Presenters:**

**Ms. Kristy Jones**  
**Ms. Cynthia Mannering**  
**Dr. David McCluskey**  
**Ms. Suanne Thurman**  
**Ms. Mary Beth Meyers**

### **MS. KRISTY JONES**

#### **Background**

Idaho is a rural State; 16 percent of its 44 counties are considered urban (i.e., population in excess of 20,000 people), 43 percent are rural (population 6 to 20,000), and the remaining 18 counties are considered frontier (i.e., fewer than 6 residents per square mile). The total population of Idaho is approximately 1.2 million.

Cancers with the highest incidence rates among Idaho men are, in order: prostate, lung, colon, and bladder cancers and non-Hodgkin's lymphoma. Among women, cancers with the highest incidence rates are breast, lung, colon, endometrial, and ovarian cancers. For both men and women, lung cancer is the leading cause of cancer mortality. For men, the other cancers causing the greatest number of deaths are, in order: prostate cancer, colon cancer, leukemia, and non-Hodgkin's lymphoma. Among women, the other leading causes of cancer death are breast, colon, and ovarian cancers and non-Hodgkin's lymphoma.

#### **Key Points**

- The Idaho Department of Health lacks the funds to conduct comprehensive cancer prevention and control programs, but it operates two categorical, CDC-funded cancer-related programs. One is the Women's Health Check Program, also known as the National Breast and Cervical Cancer Early Detection Program. Breast and cervical cancer screening is provided free of charge to low-income women ages 50 to 64 who are either uninsured or for whom insurance is a barrier to receiving screening. Providing followup under this program is very difficult, because most patients must travel up to 2 hours for an appointment, or the program must dispatch a mobile unit to perform additional tests.
- It is particularly disconcerting for the Department of Health to offer free screening and diagnosis when there are no funds to provide treatment. Thus far, local providers have been able to assist patients in identifying adequate treatment resources, except for those who have declined traditional treatment in favor of non-Western alternative treatment approaches.
- The other program administered by the Department of Health is the Tobacco Prevention and Control Program. Program goals include preventing initiation of tobacco use among minors, promoting smoking cessation among youth and adults, eliminating exposure to environmental tobacco smoke (ETS), and eliminating population disparities in smoking behaviors. Not until the most recent CDC grant has it been possible to address disparities issues. Idaho has received approximately \$170,000 dedicated to addressing tobacco-use disparities among Hispanics and Native Americans.

- As in other rural States, barriers to cancer screening and treatment in Idaho include lengthy travel distances and times that both inconvenience patients and families and increase costs. Adverse weather conditions compound access problems, and patients often choose the treatment option that requires the least amount of travel. For example, a woman living in rural Idaho opted for a mastectomy because she was unable to travel 150 to 200 miles each way to receive post-lumpectomy radiation and chemotherapy. Even if patients choose to travel to receive care, they face issues such as the availability of reliable transportation, high fuel costs, and the possibility that treatment will be interrupted if roadways are closed for extended periods due to inclement weather. In addition, paying for care is an issue. Many communities hold bake sales to try to raise money to help pay for residents' cancer treatment. Private funds to support treatment costs are very limited or nonexistent.
- Idaho's major population centers have adequate diagnostic and treatment services, but this is not the case in rural and frontier areas of the State where basic diagnostic services are lacking. These areas also have few primary care physicians or training for providers in new treatment and diagnostic services.

## **Recommendations**

- Provide funding for increased education for cancer prevention and early detection.
- Expand programs for cancer screening and diagnosis to include cancers other than breast and cervical cancer.
- Provide treatment resources for individuals who are low-income and lack health insurance, but are ineligible for Medicare or Medicaid.
- Develop national guidelines for cancer screening and treatment.
- Permit greater flexibility in the use of State and national funds to enable States to provide more comprehensive cancer prevention and early detection programs that meet the needs of State residents.

## **MS. CYNTHIA MANNERING**

### **Background**

At age 39, Ms. Mannering underwent a breast biopsy that was determined to be benign. Despite her official test results, her provider was still suspicious and sent the biopsy slides to the Walter Reed Army Medical Center, which then requested confirmation from the Stanford University Hospital. The biopsy was determined to be malignant, and 3 months later, Ms. Mannering was informed that she had non-Hodgkin's lymphoma. She was told that once her disease became more active, she would have 10 years to live, with the expectation that chemotherapy would erode her quality of life. After many additional consultations, she elected to undergo a bone marrow transplant. In 1990, however, bone marrow transplant was unusual and considered experimental; Ms. Mannering's insurance company refused coverage. Her employer fought for her insurance coverage and won, and the Cancer Center at Stanford University wrote a new protocol just for her case.

Ms. Mannering underwent 7 months of chemotherapy prior to the transplant and endured exceptionally severe side effects from the chemotherapy and extremely high doses of radiation, including a persistent fungus in her lungs, second-degree burns that caused the loss of the skin on her hands and feet, mouth sores, edema (swelling), black eyes, and the loss of her finger- and toenails and hair, including her eyelashes and eyebrows. After all that, the transplant disengrafted (i.e., failed). She subsequently received

a stem cell rescue that ultimately saved her life, although she also had a dangerous blood clot 3 months after returning home.

## **Key Points**

- One of the greatest unresolved problems for Idaho cancer patients is the financial impact of long-distance travel to receive cancer care and the cost of housing at the treatment site. To receive pretransplant treatment and maintain family support, Ms. Mannering had to rent an apartment near the treatment center in California for \$2,000 per month. These costs were in addition to the \$500,000 spent on treatment. A fellow cancer patient and friend of Ms. Mannering's traveled from Idaho to the Fred Hutchinson Cancer Center in Seattle to receive care and paid \$1,500 per month for a dirty, 400-square-foot one-bedroom apartment where she lived with her husband and parents during her treatment. Her husband, a farmer, struggled to pay these costs in addition to the medical bills and airfare. For other rural families in Idaho, who travel up to 2 hours to weekly treatments, the cost of gasoline and meals away from home are additional burdens. Distance also prevents friends and families from visiting patients who desperately need their love and support.
- The financial pressures of the current health care system have reduced the time physicians spend communicating with patients about their diseases or treatments. In addition, physicians are often intimidating to patients and presume that patients understand more about their diseases than they actually do. Because of the trauma of a cancer diagnosis, patients may not be able to concentrate on what is being said and may rely entirely on their providers to make critical decisions on their behalf. Many patients arrive at appointments unprepared to ask questions or record what is being discussed. Optimally, providers and patients should work together as a team.

## **Recommendations**

- Basic skills training should be provided so that patients can become more effective partners in the treatment process. Training could include medical vocabulary and lessons on how to ask questions and record doctors' advice. Medical appointments should include time for patients to reflect on what they have heard, followed by a return visit by a nurse to address outstanding or confusing issues.
- Physician evaluation surveys should be included as part of the appointment process to improve doctor-patient communication.
- Mechanisms must be developed to provide emotional support and psychological counseling to patients and their families as they go through the treatment process. The need for human connection during the diagnosis and treatment process cannot be underestimated, because dealing with the emotional aspects of the illness can be harder than dealing with the physical aspects of the disease and its treatment. Patients need to believe that their providers truly care about them. Better communication and continuity of care would help patients feel less frustrated and resentful and would enhance their ability to heal.
- Unexplored areas of support should be considered, such as consulting with others who have survived the cancer experience and investigating new avenues of community involvement.

## **DR. DAVID McCLUSKEY**

### **Background**

Dr. McCluskey is a general surgeon and one of 15 owners of the Twin Falls Clinic and Hospital, the only private hospital and clinic in Idaho. Sixty percent of his patient population is covered by Medicare or Medicaid or is uninsured. Thirty-five percent of his patient population is cancer patients. He also is a 22-year ACS volunteer and a member of its national Board of Directors; he is integrally involved in a number of other ACS activities.

Dr. McCluskey is a third-generation physician working in the community in which he was born and raised. Both of his parents died of cancer, and his sister is now fighting the disease.

### **Key Points**

- Regulation has placed too many constraints on the practice of medicine. Every procedure, test, or other element of care must be assigned a code from the *International Code of Diseases* (ICD-9) or *Current Procedural Technology* (CPT) manuals. Standards of care are worthwhile and important, but the coding is used only to regulate physician practice. Medical judgment cannot be standardized. To illustrate, Medicare requires patients to sign a release agreeing that, should the physician remove a suspect lesion that turns out to be benign, the physician can be held liable for fraud and abuse, and the patient will be responsible for the cost. Such requirements are punitive, call the doctor's competence into question without reason, are contrary to good medical practice, and fail to take into account that the nature of a lesion cannot always be determined by its appearance.
- Similarly, prescribed requirements for intervals for screening mammography, PSA testing, chest x-rays, or other tests do not follow the state of the science or accommodate patient needs. The proposed APC schedule is in direct conflict with current medical practice realities. There is good research, but the system does not enact laws that allow physicians to apply research results.
- Paperwork demands are excessive and limit the amount of time physicians can spend with their patients, including the important nonmedical aspects of care, such as sitting with the patients, listening to their concerns, and providing comfort. Reporting requirements have necessitated hiring additional staff simply to handle paperwork. At Dr. McCluskey's 46-bed facility, 60 of the 303 employees do nothing but make sure that medical records, coding, and billing are done according to regulations.
- The Stark Amendment prevented McCluskey, as part of a private hospital, from working with a local county facility. It took Dr. McCluskey 5 years to secure approval to participate in the National Breast and Cervical Cancer Early Detection Program because Program guidelines stipulated that Government funds could not be provided to a physician working in a private hospital setting.
- It should not be considered fraud and abuse to provide *pro bono* care to uninsured people or to veterans. The attorneys at Dr. McCluskey's hospital have advised him that if he provides care free of charge, he will jeopardize the clinic and his partners, both financially and legally.
- Dr. McCluskey believes his patients have taught him how to be a good husband, father, healer, and doctor. Through their experiences, he has learned how to live life more fully and with more immediacy.
- Legislation ultimately governs how care is provided in the U.S. and determines who will and will not have access to care. Albert Schweitzer posted a sign on his jungle hospital that read: "At whatever time you come, you will find light, help, and human kindness." Our health care system is challenged to reflect this same philosophy.

## **MS. SUANNE THURMAN**

### **Key Points**

- As one who recently relocated from New England to the West, Ms. Thurman noted that access issues in Maine and Idaho are remarkably similar. She applauded the Panel's efforts in bringing together such a diverse group of individuals to discuss cancer care issues—a singular experience in her 10-year involvement in oncology care. Too often, collaboration is only undertaken within organizations representing generally like-minded individuals. Important perspectives may be lost when the collaborative framework is so limited.
- Recognizing the barrier that distance to treatment facilities poses in Idaho, the Mountain States Tumor Institute (MSTI) operates two mobile mammography units. Over 60 percent of the women who use these mobile services have never before had a mammogram. Several Boise area providers are now collaborating on a statewide survey to identify additional barriers to receiving mammograms.
- Economic barriers to care include copayments and benefit limits that restrict access. With implementation of Medicare APCs, some copayments have increased to as much as 50 percent of treatment cost. Additional access barriers result from variations in primary care physician practice patterns regarding mammogram referrals and administration of diagnostic tests, such as PSA testing.
- The entry point into the health care system has a significant impact on access to care and the recommended course of treatment, particularly for breast cancer. Options presented to patients often are influenced by which provider they see first. Maine law now requires that providers present all women with all breast cancer treatment options. Passage of this law has had a direct impact on practice patterns in that State for breast cancer treatment.
- Patients seeking care from the Mountain States Tumor Institute are informed that they can receive care regardless of their ability to pay, but patients who are unaware that free care is available are less likely to seek needed treatment. Similarly, patients seeking care through a not-for-profit organization have a variety of options for payment, but, if they are unaware that payment arrangements are possible, they may not present for treatment.
- Though there is now one transplant program in Boise, most patients who need transplants are directed out of state for care. Out-of-pocket lodging costs can be as much as \$100 per day. The Mountain States Tumor Institute provides lodging for \$9.00 per day; for some patients, even that is too expensive, and the cost is not covered by insurance.
- Although in Idaho the cancer survival rate is more than 50 percent in adults, the perception persists that a cancer diagnosis is a death sentence. As a result, some people do not seek care.
- Access to care will not necessarily be improved by building more facilities. In many cases, excess capacity is created, but access is not improved.
- Most local facilities cannot support a research program unless the facility is not-for-profit or has secured special research funding. To participate in research, therefore, most patients have to travel to receive investigational care. The burden of travel and related costs is compounded when even routine checkups and tests associated with treatment must be obtained at the research facility; many patients are discouraged from participating if they must travel 300 miles for a simple blood test. Persistent negative perceptions of research (e.g., that patients are guinea pigs) also limit clinical trial participation.

## **Recommendations**

- Medicaid program guidelines should be modified to include out-of-area cancer care as a covered service, similar to emergency medical care. Coverage for travel and lodging should also be covered.
- Insurance should be provided for the working poor.
- Outpatient administration of cancer medications, including oral medications, should be reimbursed. Current payment guidelines require that patients receive intravenous medications for cancer treatment in the hospital in order to receive reimbursement.
- Job protection legislation is needed so that cancer patients have jobs to return to when treatment is finished.
- Greater funding should be made available to support community outreach by physicians and to underwrite community education on the benefits of disease prevention and early detection. Reimbursement reductions due to implementation of Medicare APCs will make it impossible for many facilities to conduct these important activities.
- Marketing techniques used by commercial concerns should be studied to learn how they can be applied to health promotion/disease prevention efforts.

## **MS. MARY BETH MEYERS**

### **Background**

Ms. Meyers, age 39, is a 1-year breast cancer survivor from Grangeville, Idaho, a rural community. Her treatment included a radical mastectomy followed by 3 months of chemotherapy, which she received in Lewiston, Idaho—75 miles from her home. Ms. Meyers was fortunate to have the support of family and friends, competent health care providers, and sufficient information to help her make treatment decisions.

### **Key Points**

- Ms. Meyers does not have health insurance, which is either unavailable from local employers or unaffordable. She did qualify to receive her medications for free from the pharmaceutical company. She also is currently paying off substantial medical bills.
- When she lost her hair, Ms. Myers found that the only wigs available were grey in color; as a young woman, she found this somewhat disconcerting. She chose to wear hats and scarves instead.
- Cancer support programs are an essential element in the healing process. Words of encouragement offered by individual survivors and monthly support groups provide inspiration, hope, and an opportunity to express to other cancer survivors concerns and doubts related to diagnosis and treatment.
- Lack of insurance is a major issue in rural Idaho, as many employers either do not provide health insurance or, if insurance is offered, the employee contributions are too costly.

### **Recommendations**

- Chemotherapy should be available in rural communities to avoid the need for extensive travel. Funding should be provided to enable oncologists and their staffs to visit rural

communities weekly to administer chemotherapy. If it is not possible to bring providers to rural communities, assistance with travel costs should be made available for rural cancer patients.

- The Federal Government should offer affordable insurance to help cancer patients avoid the financial drain associated with cancer treatment.
- The loss of hair accompanying cancer treatment is devastating to women. To ease the psychological impact of the treatment and hair loss, a network should be established to help supply high-quality, affordable wigs in a full range of colors and styles.

## **DISCUSSION—STATE OF IDAHO**

### **Key Points**

- Duplication in the health care system is extremely costly. Savings achieved through consolidation of services, staff, and facilities could be used to reduce the current cost of care, expand the range of services provided, or extend eligibility for insurance coverage. The Federal and State Governments could help States and localities determine what resources are available, assess areas of redundancy, and identify alternative uses of duplicative funds and resources. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) requires that consistent standards of care be provided in JCAHO-accredited facilities. This requirement results in unnecessary, costly duplication. Small communities, particularly in rural areas, are unable to finance such well-equipped facilities. Accreditation requirements should focus more on care outcomes than on facility equipment and components.
- Research efforts need to include studies of quality of life and social issues and the impact of the health care system on cancer patients. Quality care should be provided in all States, regardless of population size. Quality-of-life issues are not likely to be addressed in large research centers; these issues vary by population and State and must be addressed locally.
- Efforts should be made to train and support people who provide vital emotional support to cancer patients. Most people who mentor patients are unaffiliated with any program and seldom receive any training. They commonly “burn out” because they themselves lack the support of colleagues or peers for the emotionally difficult work they are doing. In addition, most patient mentors are volunteers. The time they spend volunteering is time away from generating income for themselves or their families. In low-income areas, few people can afford to lose income to provide volunteer services such as these. Many hospitals have resisted establishing formal training and support service programs for patient mentors because of potential liability issues.
- Uninsured cancer patients in Idaho can obtain coverage for certain aspects of their treatment by requesting funds from the Catastrophic Health Care Fund. The legislature makes funds available to each county to help pay for catastrophic health care needs; these funds are referred to as County Indigent Funds and are also available to patients with catastrophic illnesses other than cancer. Funds are limited and can be exhausted very rapidly, especially in the smaller counties. Qualifying for coverage through this fund is a time-consuming process involving a great deal of paperwork and a 6-week review period, but to date, most funding requests have been approved. For some patients with urgent medical needs, this 6-week application and review period may be too lengthy; and it is also possible that one's application could be denied. Treatment must be provided within the county in which the patient resides. Ms. Meyers indicated that this fund helped to pay for her initial cancer

treatment. Dr. Freeman observed that, despite its limitations, this funding arrangement may be unique in the Nation.

- To comply with third-party payers' reporting requirements without reducing the time he spends with his patients, Dr. McCluskey typically completes paperwork in the evenings, often until midnight.
- Dr. McCluskey indicated that Medicare-participating providers are required to use standard fee schedules for all of their patients. Thus, a physician who provides a given procedure to a patient at a discounted rate or free of charge must provide that same procedure at the discounted rate or for free to all of his or her patients. Otherwise, the physician is subject to prosecution for fraud and abuse. This situation serves as a considerable deterrent to caring for the indigent.
- Before the current regulatory system was put into place, physicians in Idaho were required to contribute approximately 10 percent of their time to providing indigent care; Dr. McCluskey suggested that returning to that system could solve many of the current problems in the health care system.
- More cancer prevention, education, and early detection programs should be developed and funded at the community level to help empower patients to protect and promote their own health.

#### **DAY ONE CLOSING REMARKS—DR. FREEMAN**

In summary, Dr. Freeman noted the special challenges associated with cancer care delivery in rural and frontier America—the great distances that people must travel to receive care; the lack of primary care providers and specialists; high levels of lack of insurance and underinsurance; cultural sensitivities that must be accommodated in cancer prevention, education, and treatment; the importance of lessons learned through failed efforts; and the need for improved communication between providers and patients. He acknowledged the extraordinary efforts of cancer survivors to overcome obstacles to receiving cancer care and the devastating financial impact that cancer treatment has had on their lives and the lives of their families.

**TOWN MEETING  
OCTOBER 12, 2000**

In addition to the scheduled testimony held on October 12 and 13, 2000, 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, and the meeting also was taped by Yellowstone Public Radio for broadcast at a later date. Dr. Harold Freeman, Chair, and Dr. Dennis Slamon represented the Panel. The meeting was moderated by Montana State Senator John Bohlinger.

**Opening Remarks**

- After welcoming the Panel and describing the purpose of the Town Meeting as part of the Panel's series of regional meetings, Senator Bohlinger noted that both of his parents had died from cancer, and that, in 1997, he was himself diagnosed with the disease. He now is cancer-free, and he indicated his gratitude for the care and support he received following his diagnosis and for the spiritual growth his cancer experience has brought him.
- Dr. Freeman emphasized that the purpose of the Panel's meetings is to put a face on the very real problems people experience as they attempt to access needed cancer information and care. Many of these problems must be addressed by changes in national, State, and local policies. Policymakers of the Nation do listen to the public, and public will for change can create political will for change.
- Dr. Slamon underscored the power of the public's voice. In the case of breast cancer research funding, the call of the cancer expert community for greater funding was insufficient to change policy; however, when the public and the advocacy community became involved, public policy changed quickly.

**Key Points**

**LOIS MUNSON, BILLINGS, MONTANA**

Ms. Munson has just had breast cancer surgery for a small lesion detected by her annual mammogram. She has had no pain except for a little soreness associated with removal of drainage tubes, has missed no time at work, and requires no additional treatment. Dr. Freeman indicated that Ms. Munson's case illustrates how far breast cancer treatment has come since the 1960s, when mammography was not routinely performed and the only treatment for her condition would have been radical mastectomy.

**REAGAN VOLK, BILLINGS, MONTANA**

Ms. Volk is a high school teacher; she was diagnosed with breast cancer several months ago. She had no family history of the disease. Her tumor was large, but it had gone undetected on two previous mammograms. Nonetheless, she believes mammography is the best option for early detection, in addition to self-examination. She was able to schedule her chemotherapy such that she did not have to take time from her teaching schedule. Although she wanted to participate in a research protocol, she could not do so, because her insurer would not have covered the cost of her care. She has been told that her prognosis is good.

Ms. Volk indicated that since her diagnosis and treatment, many students have approached her to talk about parents and relatives with cancer. Many of these patients' cancers were not detected early, principally because the patients could not afford insurance or the out-of-pocket costs of the tests. Others thought they were not at risk because they had no family history of cancer. Greater support is needed to make earlier detection of breast cancer possible and to make health care more affordable.

### **ELIZABETH REECE, CROW RESERVATION, MONTANA**

Ms. Reece is a member of the Crow tribe. The Crow reservation, covering 2.5 million acres, is located near Billings. There was little cancer on the reservation until about 10 years ago; by contrast, it now seems as if many tribe members have cancer. Many Native American women do not tell anyone about cancer symptoms they may have and do not seek care until it is too late. Many are embarrassed to have a mammogram or Pap smear. For many years, the IHS facility did not have mammography facilities, and women resisted going to a non-Indian facility. The hospital on the reservation now has a mammography machine, but because of severe understaffing at the facility, the single technician trained to operate the machine can only provide mammography one half-day per week.

In her own case, Ms. Reece had been receiving annual mammograms for some years because she had had surgery twice for fibrous breast masses while in her 20s. She skipped one year because she was caring for her mother-in-law, who was dying of lung cancer. She subsequently discovered a lump in her breast. Since she worked for the IHS, she was able to see a doctor almost immediately, and she received diagnostic mammography and surgery shortly thereafter. She elected to have a mastectomy rather than lumpectomy and is now taking Tamoxifen. Ms. Reece acknowledged that her experience with the IHS health system was quite different from that of many women who must wait months for a mammogram, even when they have symptoms. She indicated that she now wishes she had had her other breast removed as a prophylactic measure, and she may still do so.

Ms. Reece noted that some Native American women are embarrassed to return to work after cancer treatment because they worry that others will look down on them. For fear of being labeled, they also hesitate to go to support groups, yet they are eager to talk individually with Ms. Reece about their experiences. Education is needed to encourage women and men to obtain early detection tests for cancer.

### **PATRICIA McMANUS, MILWAUKEE, WISCONSIN**

People with multiple health care issues need coordinated care. Too often, health care providers fail to deal with the whole person or to work together. Dr. McManus currently is helping to coordinate the care of her sister, who was recently diagnosed with ovarian cancer but also has severe diabetes and asthma. Ms. McManus' observation has been that her sister's cancer diagnosis now takes precedence over her other health conditions; however, these other conditions cannot be ignored in the total plan for her care. Moreover, the surgeon, gynecologic oncologist, and primary care provider all appear to work independently, without regard for the total picture of her sister's health. This lack of coordination led to an avoidable medical emergency following her sister's ovarian cancer surgery.

### **ARLISS KECKLER, CHEYENNE RIVER SIOUX TRIBE, SOUTH DAKOTA**

Ms. Keckler introduced Casey, a young leukemia patient from her tribe. Pediatric cancer care is not available on the reservation, so he travels 6 hours each way by car to receive treatment. Though he now requires treatment only once per month, if he becomes ill in the middle of the night, he must be taken on a

6-hour drive to Sioux Falls to see a doctor. Casey's situation points up the special problems that distance from adequate treatment creates for children, and for adults, with cancer.

### **MARY ALICE TRAPP, ROCHESTER, MINNESOTA**

Ms. Trapp related the case of an urban Indian woman with breast cancer who goes to an urban Indian clinic in Nebraska. After surgery at the local hospital, her only discharge instructions were to return to the clinic in 2 years for a mammogram.

### **KERRY DEWEY, MISSOULA, MONTANA**

Ms. Dewey was diagnosed with breast cancer 15 years ago; she had a recurrence 7 years ago. She first presented with a palpable lump when she was 33 years old and pregnant with her second child. Her obstetrician told her she was too young to have breast cancer. Her cancer was not diagnosed until 15 months later. Her surgeon told her that all of his patients who chose lumpectomy died within a year. At that point, Ms. Dewey asked for a second opinion and became her own advocate. She feared she would soon die, and that her young children would grow up and not remember her. She had surgery, and there was no sign of metastasis at that time. For 8 years, she received regular checkups and screening. Then, however, she began to feel unwell and went in early for her checkup. A CT scan showed multiple liver metastases—Stage IV breast cancer. Ms. Dewey indicated that this was when she really knew fear.

With the help of her doctor, she was accepted into a clinical trial at the National Institutes of Health Clinical Center in Bethesda, Maryland. Over the course of 8 months, she had to leave her children every 3 weeks to travel from Missoula to Bethesda for treatment. She noted that, with a single exception, she was treated with great care and respect. The treatment was high-dose chemotherapy without stem cell rescue. It was difficult emotionally to accept that this treatment would not cure her disease, but Ms. Dewey knew it offered the best chance for extending her life. She developed several complications. She received great support from a special support group for women with advanced breast cancer, as well as from her family and friends. At the end of her treatment, her tumors had shrunk to about 70 percent of their former size. After returning home, Ms. Dewey went on Tamoxifen therapy for more than 5 years, and now is on Arimidex. Her disease is again progressing; she has six to nine tumors, the largest of which is 6 centimeters in diameter.

Ms. Dewey is grateful that she has lived long enough to see her son graduate from high school and to help her daughter buy her first bra—she considers these the important victories in fighting her cancer. Prior to her diagnosis, she had no family history of cancer; however, 2 years ago her only sister was diagnosed with advanced ovarian cancer. Though her sister's doctor was aware that she had a sibling with breast receive regular screening for ovarian cancer. After treatment with Cisplatin-based therapy, Ms. Dewey's sister has no evidence of disease.

Ms. Dewey believes she was destined to live through her own cancer experience so that she could be of assistance to her sister following her ovarian cancer diagnosis. She also speaks to groups and works individually with newly diagnosed cancer patients. Ms. Dewey's family is stronger and closer as a result of her experience.

### **CYNTHIA MANNERING, BOISE, IDAHO**

In addition to her conventional cancer therapy, Ms. Mannering had a psychic healer and tried other complementary and holistic therapies. She believes people should be more open to the possible benefit of

such therapies and should not routinely dismiss them. Ms. Mannering also noted that she mentors the 6-year-old daughter of a friend who had two bone marrow transplants but did not survive. The child, Katie, never knew her mother when she was not seriously ill, and watched her struggle and demise. Katie now lives on an Idaho dairy farm and is still severely traumatized by her mother's illness and death. She is one of many examples of the desperate need for emotional support for people with cancer and their family members.

### **ALICE BRADLEY, ROCKY MOUNTAIN CANCER INFORMATION SERVICE**

NCI sponsors the Cancer Information Service (CIS), a toll-free, tax-supported telephone resource for cancer information (at 1-800-4-CANCER). The service is regionalized so that, although all callers use the same number, each will reach the regional office closest to his or her home. The service is staffed by caring, well-trained professionals who will take the time to answer callers' questions. Cancer has its own language, and patients and their loved ones are challenged to learn this new language of medical terminology when they enter the cancer world. The CIS can be of enormous help in this regard.

### **KRISTEN NYE, MISSOULA, MONTANA**

As Advocacy Manager for the local affiliate of the ACS, Ms. Nye encouraged those at the Town Meeting to participate in the ACS Action Network. The Network publishes a newsletter to inform readers about national- and State-level issues related to cancer and how they can become involved in encouraging lawmakers to make cancer a priority. People can sign up to receive the newsletter on the ACS Web site ([www.cancer.org](http://www.cancer.org)) or write to: ACS, 3550 Mullan Road, Suite 105, in Missoula, Montana, 59808.

### **DR. DENNIS SLAMON, PRESIDENT'S CANCER PANEL**

Information is a cancer patient's most important tool. It is not necessary to have computer access to get information; the NCI has resources that can be accessed by telephone, for example. People interested in the cancer problem can have a great impact by becoming involved in advocacy. Advocates have been very effective in influencing the allocation of research and health care dollars and in the administration of support services. The ACS is one of many worthwhile cancer advocacy organizations.

### **SUANNE THURMAN, BOISE, IDAHO**

Many areas have critical shortages of health resources, while others have an excess of resources; these disparities often occur because of medical competition. Strategies must be found to minimize competition so that resources can be allocated appropriately.

### **KARENPOCHARDT, RAPID CITY, SOUTH DAKOTA**

One advantage to living in a State with a small population is that citizens have direct links to their State senators. In addition, it is easier for an individual to become involved in an issue of interest, and it is common for a group with a shared interest to work together frequently on projects or committees. This situation can sometimes produce more rapid progress on an issue than might be possible in a more populous State.

### **LIZ CHING, BILLINGS, MONTANA**

Ms. Ching, from the office of Montana Senator Max Baucus, emphasized the Senator's strong interest in cancer issues. She noted that there is interest in cancer issues in Congress and thanked the Panel for coming to Billings to elicit the testimony of citizens, which will provide valuable input on how best to direct funding to resolve cancer issues.

### **KRISTY OAKES, BILLINGS, MONTANA**

Ms. Oakes' hometown is Scobey, Montana, a remote community of about 1,000 people. The closest stoplight is in the next town, 45 miles away. Ms. Oakes' mother noticed changes in her breast and went to a doctor in Missoula. She received a mammogram, which was negative, but she knew something was wrong and returned to the same doctor. A second mammogram also was negative. A little over a year later, she went to a different doctor, who performed a biopsy; it was positive. Though she is now doing well, Ms. Oakes' mother continues to worry that had her cancer been detected earlier, it would not have been as advanced; she worries about recurrence. Ms. Oakes also recounted that her grandfather was diagnosed with terminal leukemia just over a year ago. Wishing to die at home, he returned to Scobey. Sadly, in such a small community, no hospice care was available. Family and friends cared for him as long as possible, but he eventually had to be admitted to a hospital, where he died. Ms. Oakes' grandfather's case underscores the problems of distance and access to care in remote areas.

### **DAVE BENSON, MINNESOTA**

Mr. Benson noted the importance of people coming to the meeting to provide testimony to the Panel. He quoted a recommendation of the Panel, contained in its 1999 report to the President: "It is the responsibility of legislators and policymakers to enact the laws and policies needed to ensure access to quality cancer care for all, including the interventions validated by evidence-based research processes and participation in quality prevention and treatment clinical trials." Lack of access to clinical trials has caused many cancer patients to receive less than the best possible care for their disease. The President recently signed an Executive Order requiring coverage of routine patient care costs for Medicare beneficiaries participating in clinical trials. This is a big step in the right direction, and participants at the meeting should realize that their testimony will make a big difference in helping to change public policy related to cancer.

### **WENDY LINDSAY, BILLINGS, MONTANA**

People who have cancer need information to be presented in the simplest and least intimidating manner possible. For some patients, literacy is an issue, and educational materials should be developed especially for those with low literacy. Ms. Lindsay indicated that she works with people on the reservations, conducting cancer education workshops in IHS waiting rooms, grocery stores, and other community locations. Listening to the life stories of people who attend the workshops is crucial to information transfer. Ms. Lindsay identifies strongly with the problems in dealing with providers who have little time to spend with patients. Growing up on the Fort Peck reservation, she spent countless hours in IHS waiting rooms, only to see at each appointment a new doctor who spent the little available time reviewing her history, rather than focusing on new health problems.

Ms. Lindsay indicated that for almost 2 months, she has been in contact by telephone with a woman who lives an hour's drive from Billings. This individual had an abnormal mammogram, and Ms. Lindsay arranged for her to get a diagnostic mammogram and biopsy. The biopsy results are not yet available, and Ms. Lindsay related how frightened the woman is. Ms. Lindsay believes she may be the only person with

whom this individual has contact concerning this problem, and Ms. Lindsay is committed to providing whatever assistance she may need in the future should cancer be diagnosed.

Ms. Lindsay also indicated that she is in the process of writing an application for NCI grant funding to set up a mechanism for assessing the cancer burden on the reservations. Data on Native Americans' cancer incidence and mortality are seriously incomplete, and there is no mechanism for tribes to report this information to the Montana Tumor Registry. Through her current work, Ms. Lindsay is slowly garnering support from the tribes for this reporting effort. She noted that IHS per capita health care spending in 1998 was less than half of per capita expenditures for the U.S. non-Indian population. This situation is not the fault of the IHS; it reflects broken promises made to Native Americans centuries ago. She hopes her work now and in the future will provide the information to support a more equitable allocation of resources.

### **WALTER WOODS, SOUTH DAKOTA**

Funding for breast cancer far exceeds funding for prostate cancer, in part because of the coordinated efforts of advocates. Mr. Woods, a prostate cancer survivor, indicated that he has been unable to get information on prostate cancer funding levels from the IHS. In the course of his own treatment, Mr. Woods had good support from his family and a support group of prostate cancer survivors on his reservation.

Mr. Woods travels to reservations in South Dakota to talk about prostate cancer and encourage men to be screened. He shows videos, distributes pamphlets, and speaks to groups—on the radio and at national forums. Most Native American men are resistant to screening, and it is considered inappropriate to discuss such matters, even on a one-to-one basis. As a result, they wait too late to seek help. More prostate cancer funding and educational materials are needed.

Mr. Woods encouraged those who would like to speak with him about prostate cancer to contact him at: PO Box 602, Eagle Butte, South Dakota 57625, or at (605) 964-3944.

## **OCTOBER 13, 2000**

### **OPENING REMARKS, DAY 2—DR. HAROLD FREEMAN**

In opening the meeting, Dr. Freeman reviewed highlights of the previous day's testimony. He noted that many of the States represented at the meeting are sparsely populated and geographically dispersed; people must travel significant distances to obtain cancer treatment. Presenters emphasized the need for health care providers to understand the cultural context in which services are provided. There was a consensus among presenters that poverty and lack of insurance have a deeply negative impact on health care-seeking behaviors. Further, a number of national policy issues must be addressed, such as barriers to cancer care that currently exist in the Medicaid and Medicare programs.

## **NORTH DAKOTA**

### **Presenters:**

**Ms. Tess Frohlich**

**Dr. Ferdinand Addo**

### **MS. TESS FROHLICH**

#### **Background**

Ms. Frohlich works with the Matters of Life and Death Project in North Dakota, a coalition of 50 agencies representing health care consumers and providers, education professionals, and representatives of the public health and legal communities. The project receives grant funds from the Robert Wood Johnson Foundation and the Fargo, North Dakota, Medical Foundation. Project goals include identifying the current status of end-of-life care; assessing knowledge, attitudes, and expectations of end-of-life care; and developing and presenting a comprehensive State plan for end-of-life care delivery. The Matters of Life and Death project has drawn upon a variety of data collection approaches, including community meetings, focus groups, telephone interviews, and a survey.

#### **Key Points**

- Acknowledging and strengthening relationships is a key concern for patients at the end of life. Other concerns include ensuring adequate pain control; limiting burdens placed on the family; having control over the dying process; and ensuring hospice availability. Although most patients prefer to die at home, in reality, most people die either in hospitals or nursing homes.
- There has been little public dialogue about end-of-life care preferences. Although people are beginning to share their preferences with family members, physicians are rarely included in the discussion. Physicians should actively initiate such discussions with their patients. In addition, the majority of people in North Dakota do not have living wills.
- Through its survey activity, the Matters of Life and Death Project has identified key patient needs for home care at the end of life. There is a need for comprehensive, integrated end-of-life care that provides the best chance for people who wish to do so to remain at home and to die at home. Currently, North Dakota has a model palliative care program in Fargo and hospice agencies throughout the State.

- Barriers to hospice care include inadequate education about these services, insufficient reimbursement for providers and consumers, obstructive eligibility criteria, limited program accessibility, and staffing problems.
- North Dakota has 16 hospice providers; however, because of the geographic dispersion of the population and the location of the programs, these providers are insufficient to meet the needs of the population. In particular, three of the four Indian reservations and some of the other very rural areas lack hospice service access. The Matters of Life and Death Project work group determined that a radius of 30 miles from the hospice agency was probably the range that could be served such that patients could be well maintained in the home (i.e., providing nursing, bathing, respite care, social services, chaplaincy, and support as needed). Using this criterion, far more of the State is underserved for hospice care. Because of geographic distance, 2 hours of travel time may be required for a nurse to provide 1 hour of service.

## **DR. FERDINAND ADDO**

### **Background**

Dr. Addo is a physician with Medcenter One Health Care in Bismarck, North Dakota. North Dakota is a large State; therefore, health care tends to be provided through networks of small clinics, and by two to three multispecialty medical centers. There is one NCI-designated Cancer Center located in Fargo, which is at the eastern end of the State.

### **Key Points**

- Outpatients must travel significant distances for medical care. Weather conditions in North Dakota are unrelenting and unforgiving, making distances seem even greater. Lack of health care providers such as oncologists, related specialists, and nurses is an ongoing problem. To some extent, the level and sophistication of health care services depends upon access to technology and related procedures, which at present is inconsistent.
- Third-party payer reimbursement levels vary according to provider size, type, and location. Rural clinics rendering basic medical care services receive a lower level of reimbursement than large medical centers providing the same services. Such variations in reimbursement discourage service delivery in the rural clinic setting, forcing patients to travel outside their communities to receive care. For example, many patients with prostate cancer are treated with intramuscular Lupron injections. Rural clinics are reimbursed \$50 per Lupron injection, although the cost of the drug is actually \$650. If the same injection is provided at a major medical center, the full cost of the drug is reimbursed. Similarly, if Erythropoietin is administered in a clinic setting, it is reimbursed fairly, but if it is dispensed through an outreach effort or home nursing agency, reimbursement is insufficient to cover costs. Although an extensive telemedicine network has been established, most consultations are not reimbursable.
- North Dakota provides grants for the Women's Way program, through which low-income women receive annual mammograms and pap smears. This program has been working well. Women who are not screened through the program, however, must receive services in accordance with Medicare and Medicaid regulations. These regulations strictly mandate that mammograms cannot be provided more often than every 365 days (rather than every year or 12 months), leaving little flexibility for accommodating either providers' or patients' schedules.

- To be eligible for hospice care, patients must have a life expectancy of 6 months or less. This requirement poses special challenges for physicians who believe that life expectancy is extremely difficult to predict. As a result, physicians are reluctant to initiate a hospice referral until very late in the disease process, depriving patients of access to hospice-related services that could improve their quality of life. In addition, Medicare hospice eligibility requirements stipulate that the primary family caregiver must live in the patient's home; for many people, there is no such person, although a neighbor or friend could provide the necessary care.
- Third-party reimbursement does not keep pace with advances in medical treatment. If practice patterns deviate from what payers recognize as the standard of care, reimbursement will be denied. Providers rendering state-of-the-art treatment, particularly those administering certain medications, often must respond to third-party payer inquiries and challenges. Securing approvals can take months. This situation stifles the delivery of high-quality medical care.
- In many cases, patients participating in cooperative group clinical trials do not have to pay for the medication they receive, but there are costs associated with administration of the drug, such as nursing care and intravenous supplies. Since Medicare will not reimburse patients for care provided in a clinical trial, patients often are charged as much as \$100 to \$200 per month to cover the cost of administering the medication, even though the medication itself is provided free.
- Due to the limited availability of local providers, patients must travel as much as several hundred miles to obtain care at clinic sites. Because of the inflexibility of clinical trial treatment protocols, patients often must make several trips to the clinic within short time periods; this situation causes considerable physical and financial hardship. To limit patients' travel burdens, greater coordination is needed between clinical trial-related health care delivery and general medical care delivery.
- Currently, no reimbursements or incentives are in place for providing the wellness services (e.g., nutrition counseling, lifestyle changes) that are an important part of comprehensive cancer care. Comprehensive care for cancer also should take into consideration access problems, transportation needs, and the effects of the disease on the patients' families.
- Efforts should be made to define what is meant by "the best" cancer care. Patients often are confused by conflicting information about treatment options because there is a lack of consistent treatment guidelines from authoritative bodies. The lack of these standards also hampers provider efforts to guide patients.
- Funds should be provided to encourage people to take better advantage of prevention services, screening, counseling, and education related to cancer.
- Incentives should be established to help attract health care providers to rural areas.

## **STATE OF NORTH DAKOTA—DISCUSSION**

### **Key Points**

- Ms. Frohlich noted the racial and ethnic disparities in cancer deaths reported in the Native American and non-Native American populations in North Dakota. The average age at death of all Native Americans in North Dakota is 50 to 55 years. Among non-Native Americans, the average age at death is 70 to 72 years. These statistics have a profound impact on the nature of end-of-life care needs.

- Native Americans, particularly those living on North Dakota reservations, have limited access to end-of-life care. Hospice services are available on only one of four reservations.
- Native Americans living on reservations are eligible for health care coverage through the Indian Health Service (IHS), Medicare, and Medicaid. It can be difficult for patients and providers to determine which payer has primary reimbursement responsibility.
- The population of North Dakota is primarily Caucasian. Native Americans comprise the largest minority group (approximately 10 percent); the African-American and Hispanic populations are small and clustered in the cities and around military bases.
- Patients who are dying seek as much control over their lives as possible. Control can be interpreted in many ways, including enabling patients to take control over their bodily functions and their environment. Patients also want to be able to designate the type of care they receive, to have adequate pain control, and to ensure that they are not a burden on loved ones. Since North Dakota is a very conservative State, discussion of end-of-life issues typically does not include euthanasia.
- Restrictive protocol testing and treatment schedules discourage clinical trial participation when patients must repeatedly drive long distances because testing cannot be grouped with other services without violating the protocol. Industry trials tend to be somewhat more flexible than NCI-sponsored trials in this regard.
- Dr. Addo indicated that approximately 700 new patients are seen each year in his clinic's oncology division. There are 3 practicing physicians in the clinic, each seeing approximately 120 patients per month. Dr. Addo clarified his earlier statement regarding the low level of lack of insurance in North Dakota. Billing data from his clinic indicate a low level of lack of insurance among clinic patients (approximately 3 percent), but uninsured levels are much higher in other parts of the State. Approximately 90 percent of the patients served in the clinics are Caucasian.
- Public policy should focus on addressing access issues. Medcenter One Health Care has invested a great deal of effort in developing and staffing a network of primary care facilities. Given the limited number of facilities in the State, efforts should be made to support the delivery and equitable reimbursement of cancer treatment in local settings.
- In medical shortage areas, telemedicine has increasing potential to expand health care access, despite possible privacy and liability concerns. However, reimbursement is not provided for telemedicine-related medical services, such as consultations. Third-party payer reimbursement policies should be expanded to include telemedicine.
- Dr. Slamon expressed concern regarding the disparity between reimbursement provided to rural health clinics and to large medical institutions for the administration of identical medications. This issue needs to be addressed further, not only in the States represented at the Panel meeting, but perhaps on a national basis. He invited Dr. Addo's staff to provide further testimony on this significant problem.
- Ms. Pochardt, a cancer administrator from Rapid City, South Dakota, emphasized that medication reimbursement disparities is a Federal issue. The rural health clinic reimbursement caps are set by the Federal Government, not the intermediary. When a drug is administered outside the provider setting (e.g., administered by a family member or community health nurse), it is considered a take-home drug.

- Ms. Pochardt provided further clarification regarding Medicare and Medicaid eligibility issues. Medicare Part A (inpatient hospital care) eligibility for reservation residents is a function of whether or not the individual has Social Security credits from previous employment of a specified duration. Premium payments are required to obtain coverage under Medicare Part B (physician services). Medicaid eligibility and benefits vary by State. It is not uncommon for people to be eligible for Medicare, Medicaid, IHS, and Veterans Administration (VA) benefits simultaneously. IHS is ostensibly the payer of last resort.
- Because the nuclear agent needed to perform PET scans has a brief half-life, the imaging facility must be located no more than 2 hours from the site where the nuclear agent is produced. Currently, no source of the required nuclear material is within a 2-hour range of Rapid City. Rapid City's tertiary care facility needs to have the most up-to-date imaging and diagnostic equipment but will be unable to provide PET scans unless nuclear supply sites are established in or near the Rapid City area.
- No focus groups have been conducted with people living on the three reservations that lack access to hospice services. Hospice agencies serving the surrounding areas indicate that insufficient staffing prevents them from providing services to the reservations.
- Dr. Freeman questioned whether the hospice concept is consistent with Native American culture. Ms. Frolich indicated that hospices' holistic approach to end-of-life care includes a number of elements—such as medication, nursing care, special care, and communication—that appear to be valued by Native Americans and non-Native Americans alike. It is unclear, however, whether Native Americans would be receptive to these services if they were delivered by non-Natives.
- Unless a hospice program conforms to the federally mandated program structure, patients and providers will be unable to be reimbursed for services rendered. This restriction poses considerable hardship in rural areas, where communities may be unable to meet all of the hospice requirements. Hospice program regulations need to have greater flexibility to enable more providers to render hospice care.
- Native Americans in South Dakota place a high value on being able to die comfortably and peacefully at home, and they are supportive of the hospice care concept. Efforts are underway to establish hospice services on the reservations, but it is unresolved whether the program will be administered under tribal auspices or by the IHS.
- Hospice philosophy reflects a holistic approach to health care delivery and the dying process. Programs typically include skilled nursing, spiritual care, social work services, respite care provided through volunteers, and a primary caregiver.
- When patients enter hospice care, they lose their Medicare benefits, even if their hospice inpatient stay is limited. If the patient then decides to return home, he or she must reapply for Medicare coverage, a complicated and arduous process.
- To be eligible for hospice coverage, a patient must be diagnosed with a terminal illness and be determined to have 6 months or less to live. Estimating life expectancy is extremely challenging for health care providers. If the patient outlives the initial prognosis, it is very difficult to retain hospice coverage. Thus, physicians are reluctant to refer patients to hospice until they are relatively certain about the patient's life expectancy, and the usual result is late referral to hospice such that patients receive hospice care for an average of only 1 to 2 weeks prior to death. These referral delays prevent patients and families from having appropriate access to valuable supportive services.

- Patients desiring hospice care also must agree to forego any further treatment with curative intent; this can be an emotionally difficult decision. Hospice focuses on preparation for death and creating the most comfortable physical and emotional environment possible.

## **MINNESOTA**

### **Presenters**

**Ms. Mary Manning**

**Ms. Barbara Ingalsbe**

**Ms. Mary Alice Trapp**

**Ms. Coral Houle**

**Ms. Ceci Shapland**

## **MS. MARY MANNING**

### **Key Points**

- Cancer registries are important both in Minnesota and throughout the country. Registries provide information that is essential to resource allocation. Managed care has had a negative impact on the level and quality of cancer data reporting. This is because hospital staff face increasing pressure to contain costs and provide higher levels of service without a corresponding increase in resources. The quality and reliability of registry data have suffered as a consequence.
- Minnesota is racially and ethnically diverse. Minneapolis/St. Paul has one of the largest urban populations of Native Americans and Somalis and a growing percentage of blacks and Latinos. However, no population group in Minnesota uses prevention and early screening services optimally. Cultural diversity and a multiplicity of languages make health care delivery even more challenging. For example, emergency room staff in Hennepin County have documented the use of 91 different languages to communicate with their patients.
- In Minnesota, black women have much lower breast cancer survival rates than white women. Though many factors contribute to the lower rates in this population group, the underlying element is income disparities that lead to disparities in health care coverage and quality of health insurance. In reality, it is not Minnesota's poorest residents who lack quality health insurance, since Medicaid provides extensive coverage for cancer-related procedures. However, people with modest incomes (100 to 250 percent of the national poverty level), face great financial hardship. Many of these individuals do not qualify for Federal program coverage, and, therefore, a cancer diagnosis often results in financial ruin. One approach to addressing this issue would be to provide universal access to health insurance.
- Television is an effective tool for communicating cancer prevention information. In Minnesota, television advertisements have been particularly effective in raising awareness of breast and cervical cancer prevention and screening among low-income (at or below 250 percent of the Federal poverty level) underinsured and uninsured women. A 13-day television campaign about free and low-cost mammograms resulted in approximately 2,100 calls to the State Health Department for additional information, and approximately 600 women received screening in one week. Television advertising for mammograms was considerably less expensive than other advertising options (\$66.11 versus \$125 per person). Television ads included female public figures, such as the Mayor of Minneapolis (an African-American

woman), other city workers, Fire Department representatives, and Mayor's Office staff, who served as role models for breast and cervical cancer prevention.

## **Recommendations**

- Given the success of Minnesota's television campaign, increased community pressure should be placed on major networks to provide primetime slots for prevention education at substantially reduced rates. Special efforts should be devoted to developing the most appropriate messages to change people's health care-seeking behaviors.

## **MS. BARBARA INGALSBE**

### **Background**

Ms. Ingalsbe lives in Paynesville, Minnesota, a community with a population of 2,275. In May 1998, she found a lump in her arm and immediately went to her doctor. She was told it was a harmless lipoma and advised that it did not need to be removed. Three months later, the lump was larger, and Ms. Ingalsbe insisted that it be removed, although she still did not suspect it might be cancer. Upon attempting to remove the lump, the physician realized the seriousness of the situation. Ms. Ingalsbe was sent to the University of Minnesota Medical Center, 100 miles from home. A biopsy revealed a pleomorphic soft tissue sarcoma, Stage III-B. Ms. Ingalsbe worries that the delay in diagnosis may have prevented her from seeing her children reach adulthood.

During her treatment, Ms. Ingalsbe drove 200 miles daily for 7 weeks to receive a 45-second daily dose of radiation. She does not believe she will ever be entirely cancer-free, but she is committed to doing everything she can to stay healthy and take advantage of early detection methods.

### **Key Points**

- Ms. Ingalsbe applauded the efforts of the Panel and noted the courage and strength of the cancer survivors who provided testimony, as well as the high degree of dedication evidenced by the physicians and organizations in the Midwest who support cancer patients. She noted the importance of bringing together such a diverse group of people and for providing a forum for cancer patients to express their concerns about cancer care access, delivery, and quality.
- There is a lack of information and resources available to support people with rare cancers, such as sarcoma. Although the incidence of sarcomas and other rare cancers is lower than for many other types of cancer, they generally are more deadly and therefore should not be overlooked by the research and provider communities.
- Internet-based support groups can be valuable for cancer patients, particularly when there may not be any support groups available locally. Support from other survivors is crucial; as loving as family and friends may be, they cannot understand the cancer experience the way another person with cancer can.
- Patients must take responsibility for educating themselves about their disease so that they can participate effectively in informed health care decisionmaking. This includes developing an understanding of medical terminology, treatment alternatives, and relevant statistics. One of the most valuable information sources about cancer is NCI's Physician Data Query (PDQ) database that provides information on the latest developments in cancer treatment.

- Patients must be effective partners in their treatment process. Physicians and other care providers must be willing to respond to questions and to provide sufficient explanation to patients regarding their course of treatment. For most patients, information is empowering; it is likely that only a small percentage do not want to know about their disease.
- Patients' emotional states have a direct impact on how they tolerate cancer treatment and, ultimately, can influence the outcome of treatment. More attention should be focused not only the physical needs of cancer patients, but on their emotional needs, hopes and dreams, fears, and their desire to live as long and meaningful a life as possible. The importance of a good doctor-patient relationship cannot be overemphasized. In addition, technically skilled cancer care providers must not ignore their patients' fears of death and dying. In the current health care climate, physicians are not reimbursed for listening, yet the power of the mind in the healing process must not be overlooked or underestimated. As cancer is increasingly viewed as a chronic, rather than a deadly, disease, it is more important than ever for providers to do what they can to help patients stay the course emotionally.

### **Recommendation**

- Hospitals, community centers, and others should help cancer patients access information and support networks via the Internet, particularly in rural areas where travel poses a considerable hardship. Resource rooms that include a lending library of books, videotapes, audiotapes, and other materials should be established to enhance patient education about cancer.

## **MS. MARY ALICE TRAPP**

### **Background**

Ms. Trapp is Director of the Native Women Enjoying the Benefit (Native WEB) program at the Mayo Clinic in Rochester, Minnesota. The Native WEB began as a 3-year CDC grant program focused on early cancer detection and screening. It grew out of a request from tribal members in the Aberdeen and Bemidji areas of the Indian Health Service to develop a program to deliver culturally acceptable care to Native women and their communities. The program included using women, rather than the male physicians practicing in these areas, to provide Pap smears and breast exams to Native American women. After the grant expired and efforts to seek additional funds from CDC and NCI failed, the Mayo Cancer Center provided the necessary funding. The mission of the program is to eliminate unnecessary cancer deaths among Native Americans and all other underserved women.

The Native WEB currently consists of two programs. The Native Women Enjoying the Benefit Through Community Education program works with tribal Community Health Representatives (CHRs) to deliver culturally acceptable messages regarding the importance of cervical, breast, and prostate cancer screening. The Native WEB Provider Training program includes 40 hours of didactic lab and clinical training for nurses, physicians, physician assistants, and others. In Alaska, the program trains health aids who live in the villages, because there is no physician or nurse practitioner. Also included is the Train the Trainer program, which enables more individuals to render care to tribal women.

### **Key Points**

- The goal of the Native WEB is to increase the number of women receiving annual cancer screening to at least 80 percent, thereby decreasing cancer deaths. Since January 1995, Native WEB nurses have provided breast exams and Pap smears in Oklahoma, Missouri, Kansas, and Texas. Women who present with symptoms are referred to a physician.

- Breast cancer rates in Native Americans in the Aberdeen and Bemidji areas of the Indian Health Service are equal to or greater than those of Caucasian women, and their survival rates are the lowest among all ethnic minorities. This disparity may be attributable to lack of access to appropriate diagnostic and treatment technology. For example, there are only 66 mammography machines for 566 federally recognized tribes.
- American Samoa only recently acquired a mammography machine. Previously, Samoans had to fly to Hawaii to receive a mammogram. Of the 10 mammograms performed, 5 were positive for cancer. However, the mammography machine is now out of film, and there is no money to buy more, so no additional mammograms can be performed.
- Special attention was given to the naming of the cancer screening clinic to enhance cultural acceptability. The clinics are referred to as “Circle of Life Clinics” or “Well Woman Clinics.” This has had a positive affect on women’s attitudes and willingness to seek cancer-related care. Many women—not just Native women—are uncomfortable with illness-oriented programs, or even saying the words *breast exam* or *Pap smear*.
- Continuity of care is a major issue for Native Americans. Ms. Trapp recounted the case of a woman who had repeated Pap smears, but no treatment, despite multiple abnormal results. The temporary providers simply kept repeating the test without consulting her patient record.
- Although many Native American communities do not have the most sophisticated technology to deliver care, Community Health Representatives can clearly disseminate valuable information about cancer prevention and early detection. To help women overcome their hesitation and better understand the importance of Pap tests, the cervix was described as the “doorway to the world” for their babies and grandchildren.
- Even in the urban Indian setting, distances or waiting periods can be long. In Lincoln, Nebraska, for example, the waiting time for a Pap smear is 6 months.
- Data on the Native American population are sorely incomplete.
- The Native WEB program is attempting to obtain grant funding for a computer network to link nurses in the field. Many of these nurses work alone at their sites.

## **MS. CORAL HOULE**

### **Background**

Ms. Houle, from Bloomington, Minnesota, is a 32-year survivor of breast cancer, including 23 years after a recurrence. She has been a volunteer for the American Cancer Society for over 30 years and is Vice President and President-elect of the Board of the Midwest Division. Ms. Houle also is the Chair of the Minnesota Advocacy Committee and a former Mayor of Bloomington, Minnesota.

Minnesota has relatively low cancer mortality, ranking 42<sup>nd</sup> among all States. Yet the State has the highest percentage of women aged 50 years and older who reported not having received a mammogram within the past 2 years. The youth smoking rate in the State is above the national average, and minority communities experience disproportionately high levels of cancer incidence and mortality.

Nine percent of Minnesotans lack health insurance. The State poverty level is 8 percent.

## **Key Points**

- Higher cancer incidences and mortality rates among minorities and medically underserved populations demonstrate that benefits from scientific advances in cancer control do not equitably accrue to all Americans. Although existing cancer-fighting tools do work, they are not fully utilized because they are not universally accessible.
- Substantial communication barriers inhibit cancer information dissemination, particularly to those whose culture and language differ from those of the mainstream and for those who live in remote areas of the State. These populations find it difficult to find the best medical help and to communicate with health care providers. The ACS Midwest Division is developing a statewide Navigator program to address common barriers faced by cancer patients. An ACS Navigator links people with cancer to appropriate information and treatment resources. Considerable emphasis is being placed on developing a program that is sensitive to the language barriers and cultural differences among minority communities.
- Recognizing the barriers that geography and lack of transportation pose to receiving health care, the ACS is rebuilding its volunteer transportation program. Referred to as "Road to Recovery," the program is focused on expanding the ranks of volunteers who can provide transportation assistance for people undergoing cancer treatment.
- A former elected official, Ms. Houle underscored the power of the voice of the people. Marshaling the public will to advocate for solutions to the cancer problem must be done on the local and grassroots levels. This will occur only if people recognize how cancer affects their local communities. Those involved in cancer research and intervention have a responsibility to help the public understand the cancer burden in their communities. The NCI initiatives previously mentioned are exciting because they are community focused. Likewise, the ACS is conducting community assessments to help people understand the different burdens of cancer each community bears and the support efforts required to meet community needs.

## **MS. CECI SHAPLAND**

### **Background**

Ms. Shapland is the Executive Director of the Women's Cancer Resource Center in Minneapolis, Minnesota, a grassroots organization developed by cancer survivors to provide information, advocacy, support, and referral assistance to women with cancer. She also is a 7-year breast cancer survivor. The Resource Center provides women with cancer-related information and access to a library of cancer materials, health care referrals, and cancer support groups.

## **Key Points**

- Survivors struggle to find information about their disease. Those in minority communities may face a particularly difficult challenge in this regard because of cultural taboos against discussing cancer. Many cancer patients feel their health care providers do not spend enough time discussing their condition and providing information. Managed care has had a negative impact on the doctor-patient relationship by demanding increased provider productivity in the absence of additional resources. Higher patient loads have resulted in less time for communication, leaving patients with unanswered questions and unresolved concerns and fears.

- A new project of the Center, Woman to Woman, focuses on the African-American community, providing one-to-one assistance to women diagnosed with breast cancer. The staff provides emotional support, transportation, and assistance in interpreting medical information. Though this individual approach may not be the most *cost-effective*, it is the most *effective*.
- Young women experience discrimination in the health care system because providers do not generally consider a possible cancer diagnosis in a young person reporting cancer-related symptoms. Since this is relatively uncommon, their cancers may be overlooked. Cancer treatment-related issues among young single women can be particularly difficult to deal with, especially if the treatment will result in body image changes. Young married women who have children naturally are concerned about staying alive to raise those children. Those in college who must leave school to undergo treatment often lose insurance coverage and are forced to enroll in their parents' insurance through COBRA. However, after COBRA coverage expires, they are left with a preexisting condition that may or may not be covered under another insurance plan. Young people also need and seek the freedom to change jobs for professional advancement. If they have cancer, they may be forced to remain in their present jobs to retain insurance coverage.
- There is a great deal of discrimination against homosexuals in the medical field. Homosexuals, particularly older lesbians, are hesitant to go for screening. The Center has established a lesbian support group to address the special lifestyle and partnership issues that arise in their cancer treatment.
- It is unclear whether or not special programs exist in Minnesota that provide breast cancer screening for women with physical disabilities. Such specialized programs are needed and should include developing and providing large-print materials, providing interpreters for the hearing impaired, and instructing women with spasticity disorders—or their caregivers—in breast examination.
- Pediatric cancer cases have increased by approximately 20 percent over the past 20 years. Research has demonstrated that only 5 to 10 percent of pediatric cancers are genetically linked.

### **Recommendation**

- NCI should provide more funding to identify environmental causes of cancer.

## **DISCUSSION—STATE OF MINNESOTA**

### **Key Points**

- Ms. Ingalsbe successfully obtained information about sarcoma by contacting NCI's Cancer Information Service (toll-free at 1-800-4-CANCER). The staff were well informed and provided useful information. However, Ms. Ingalsbe only learned of the number coincidentally; she read the number in a letter published in Ann Landers' column while in the hospital recuperating from surgery.
- As a result of pressure from managed care companies, hospitals have cut costs and staff. This has had an adverse impact on timely and thorough data reporting, since registries are not a priority when compared with patient care delivery. Consequently, the Minnesota Health Department has provided its own medical records staff to abstract Registry data. This is a costly endeavor for the Health Department.

- Dr. Freeman noted that national experience regarding breast cancer detection rates through mammograms is significantly lower than the rate achieved in the Minnesota program described by Ms. Manning (1 cancer for every 118 mammograms). Nationally, the number is 8 cancers per 1,000 examinations; Dr. Freeman indicated that at the hospital where he works in Harlem, the rate is 16 per 1,000 examinations.
- It appears that Federal and State funds are not as readily available to support cancer screening programs for men. The community assessments underway at the Midwest Division will be used to establish resource allocation priorities. Program planning has been hampered by a lack of good baseline data at the community level. Generally, women communicate more with each other and tend to reach out for assistance, whereas men typically do not. Because of this difference, it is a challenge to provide men with the kind of information and services that will encourage them to utilize medical services.

## **WISCONSIN**

### **Presenters:**

**Dr. Patricia McManus**  
**Dr. Jeanne L. Connors**  
**Ms. Kathleen Murphy-Ende**  
**Mr. Robert Speer**

### **DR. PATRICIA MCMANUS**

#### **Background**

According to 1990 census data, there are approximately 680,000 people in the city of Milwaukee, and 1.2 million in the surrounding metropolitan area. Approximately 30 percent, or nearly 200,000 people, are African Americans. It is expected that the 2000 census will show a rise in the African-American population to approximately 40 percent of the Milwaukee metropolitan area. Statewide, minorities comprise 10 percent of the population; of this 10 percent, half are African Americans.

Dr. McManus directs the Black Health Coalition in Milwaukee, Wisconsin. She works primarily with the working poor in the community.

#### **Key Points**

- In Milwaukee, there are a high number of working poor who lack health insurance. False assumptions are often made that many African Americans are on welfare and, therefore, are Medicaid-eligible. In fact, many work two or three low-income jobs, none of which provides health care insurance. When a major illness strikes, not only do African Americans lack health insurance, they also do not have the financial reserves to support themselves through the illness.
- African Americans with cancer are likely to have multiple medical conditions, such as diabetes, hypertension, and asthma. They generally do not participate in community-based health promotion activities and behaviors, which has a significant impact on cancer prevention and treatment efforts.

- Significant levels of institutional racism, sexism, classism, and provider bias still exist at all levels of society, including in the health care system. It is unreasonable to think that people behave one way in their lives outside a medical facility and another way once inside it.
- The Tuskegee syphilis experiments and the 1990 measles vaccine issue, as well as other incidents, have left a legacy of mistrust of the health and medical systems among communities of color.
- Approximately 80 percent of people with health insurance in Wisconsin are enrolled in some type of managed care program. Most of these patients can only receive their cancer care from managed care contract providers. It is not uncommon for patients to have to travel great distances to obtain care, even though similar or better facilities may be located within their own communities.
- As a result of devolution and the accompanying transfer of Federal funds to the States (block grants), communities with small minority populations receive considerably fewer resources than needed because, while they may represent a small percentage of the total population, their health care needs tend to be disproportionately high. Therefore, resource allocation based on population percentages generally results in inadequate funding levels.
- The ACS, especially in Milwaukee, has not been a friend to the African-American community. ACS rarely hires people of color, especially at high levels in the organization. The organization is not highly involved in the local community and, thus, is less likely to be as effective as other community-based programs. Yet the ACS and other larger organizations are more likely to receive funding for minority-oriented programs, effectively blocking minority community-based programs from building capacity within the communities.
- There is a tendency to develop disease or problem-specific health care programs, such as special efforts focused on HIV, prostate cancer, or breast cancer. While specialized interventions and information-sharing may be needed, it would be more effective to portray these programs as being focused on general health improvement and wellness. Doing so may improve the appeal of programs among the target population and avoid the stigma potentially associated with a particular health issue. In addition, the program develops a positive presence in the community, and its assistance with specific health issues is more likely to be accepted. For example, a Milwaukee community center has recently started a men's health clinic. While its primary focus is HIV, this is not made explicit, and the program has been successful in getting men to come in for screening and other health concerns.
- Prevention and screening are keys to addressing the higher cancer mortality and later detection of disease common to African-American populations.
- Health promotion efforts and messages need to be delivered from one community member to another. This approach helps ensure that the message is delivered in a culturally appropriate manner and is more likely to be accepted, particularly when it comes from someone who has a deep understanding of the reality of the inherent daily pressures.
- Funding of faith-based organizations (such as black churches) to provide palliative and end-of-life care, as well as to promote healthy lifestyles, can be particularly effective.
- As part of NCI's ASSIST project on tobacco control, Wisconsin was able to target programs to at-risk, underserved, and minority populations. The State was held accountable for ensuring that these populations' issues were addressed. When NCI funding for ASSIST ended, and the project was transferred to the CDC, the funding also stopped, because, instead of State accountability, the funds went to local and regional health departments. Community

organizations received nothing. Federal oversight is still needed to ensure that underrepresented groups receive needed support.

## **Recommendations**

- There is a need for advocacy-related coalition-building versus coalitions focused on expanding health care delivery networks and provider services. Advocacy-related coalition building focuses on putting resources within the community and empowers the community to hold providers accountable for services delivered. The Black Health Coalition received an HIV-related Congressional Black Caucus grant that enabled the Coalition to work directly with members of the community to develop and implement a program from its inception. This is in contrast to situations in which the funding goes to a provider organization that then decides if and when to involve the community. The funding needs to go directly to the community itself.
- More funding is needed to support cancer prevention and screening, particularly in the African-American community. Although the incidence of cancer is not markedly different between African Americans and other populations, African-American cancer survival rates are much lower because of late detection and, therefore, delayed treatment.
- Additional funds should be provided for community-based research, particularly as it relates to clinical trial promotion and participation. Community-based coalitions can provide valuable assistance in overcoming trust issues that often stand in the way of minority participation in clinical trials.
- There should be more minority (and grassroots-level) participation in all phases of research—from the design through the dissemination stage. This is particularly important in the African-American community, especially when the research is focused on identifying social and behavioral issues impacting people's health. There is a tendency to believe the bias that only health departments, universities, and medical centers can accurately assess what is happening in local communities and develop effective interventions. This is not necessarily the case, particularly with respect to disparities. To ensure that the research has merit and provides value, the local community must be included.
- Better coordination of care is needed for people with multiple health concerns; providers have become so specialized that patients no longer are treated as whole people. Training and policy directives are needed to encourage providers to take a more holistic approach to care.

## **DR. JEANNE L. CONNORS**

### **Background**

Wisconsin has a total Native American population of about 40,000, approximately half of whom live on the 11 reservations in the State. The remainder live predominantly in Green Bay, Milwaukee, the Fox Valley cities, or in Minneapolis, Minnesota. Most of the reservations are located in the northern part of Wisconsin, an economically depressed and sparsely populated region with no major metropolitan areas and a lack of high-quality, accessible education and medical care.

Cancer is the second leading cause of death among Native Americans in Wisconsin. Historically, Native Americans have had lower rates of breast, uterine, ovarian, prostate, lung, and colorectal cancers; however, the incidence of breast cancer among Native American women appears to be rising. Native

Americans have particularly high smoking rates—in part due to low cigarette prices—which have resulted in higher rates of lung, nasal, and sinus cancers. In Menominee, 49 percent of adults smoke.

Although Native Americans may have a lower overall incidence of cancer, their mortality from cancer is much greater than that of non-Native Americans. This disparity is attributable to lack of screening and early detection, treatment delays, and inadequate care. Five-year survival from colorectal cancer is 39.7 percent for Native Americans and 53 percent for non-Natives; only 46 percent of Native American women survive breast cancer, compared with 76 percent of non-Natives.

## **Key Points**

- It is difficult to obtain accurate cancer-related data for Native Americans. Often, death certificates are completed by a physician other than the primary care provider, and cancer may be overlooked as the primary cause of death. Cause of death may instead be reported as kidney or heart failure, which may have been the proximate cause of death but not the underlying causative condition.
- Racial misclassification of Native Americans is common. Native Americans are often classified erroneously as Caucasian, Mexican, or Filipino by inexperienced providers who make guesses rather than obtain the information from the patient.
- Median age data are calculated for only 23.4 percent of Native Americans, so age-adjusted data are difficult to calculate, and the limited data from southwestern tribes and Alaska Natives are not generalizable to all Native American communities. Data on cancer in urban Natives (50 percent of all Native Americans) are scarce, since information on these populations is not included in IHS databases.
- Cultural barriers limit the ability to obtain mortality data directly from the tribes. Because the number of tribal cancer deaths is small, tribes resist releasing data that could compromise the anonymity of patients and their families.
- Poverty and unemployment are high on the reservations, and poverty is time-consuming; it is hard to take care of one's health when one is struggling with poverty every day.
- Although casino profits have been used to improve Native American health care, there is still a shortage of skilled physicians and a lack of state-of-the-art medical technology.
- In 1998, the University of Wisconsin Comprehensive Cancer Center launched an educational campaign for tribes entitled “Important Things You Need to Know About Cancer and Cancer Survivorship.” Ten Wisconsin tribes were represented among 150 participants. A 1-year followup survey, “What Do You Know About Cancer?” was conducted to identify Native American beliefs and ideas about cancer. Through these initiatives, a number of barriers to cancer screening, diagnosis, and treatment were identified. For example, with regard to cancer education and information dissemination, respondents indicated that there was not an ample supply of culturally sensitive and easy-to-understand literature, and there was a lack of people who could talk directly with community members about cancer-related issues and information. Other barriers included the lack of transportation and the need to travel great distances for care, lack of female health care providers, lack of Native American health care providers, and a general lack of health care providers of any type.
- Native Americans are averse to open discussion about cancer and are uncomfortable merely using the word *cancer* for fear that speaking about it will cause it to occur. This situation poses considerable challenges to health educators and health care providers to create culturally sensitive and effective methods of communication about the disease. Having cancer

is seen as a punishment, which is one reason some Native Americans do not wish to discuss it. Cancer is also believed to be contagious, and it is further believed that surgery can cause the cancer to spread. A widespread misconception is that cancer “runs in the family” and therefore, everyone in the family will eventually be stricken.

- Although Native Americans may outwardly downplay the importance of traditional healers to avoid ridicule, there is still a reliance on traditional Native American medicine. Therefore, the importance of traditional medicine should not be ignored, and efforts should be made to incorporate it into the treatment process.

### **Recommendations**

- Explore and respect cultural beliefs about illness and healing. Include extended family members in discussions with doctors and other medical personnel. In Native American cultures, other relatives are very important and may often be even more important to patients than spouses.
- Incorporate Native American healing practices into western medicine and respect cultural differences in the approach to cancer care.

### **DR. KATHLEEN MURPHY-ENDE**

#### **Key Points**

- Cancer treatment advances have led to the need for progressive symptom management and intense psychological, educational, social, and spiritual support to be initiated at the time of diagnosis.
- Palliative care has been part of the foundation of nursing science for decades, but only recently has it received such attention and focus. Palliative care is defined as the active total care of patients whose disease no longer responds to curative treatment, focusing on the quality of life and integrating the physical, psychological, spiritual, and social aspects of care. Within the palliative care model, dying is viewed as a natural process, and the goal of care is to provide the best quality of life through symptom control. The principal focus of symptom control is pain management, and it extends to a variety of challenging disabilities and conditions.
- Pain management is at the heart of the palliative care process. Research indicates that 40 to 80 percent of patients with cancer experience inadequate pain management; 60 to 90 percent with advanced cancer have severe pain; 42 percent with metastatic disease are undertreated; and 81 percent with pain report impaired function. Yet 90 percent of cancer pain can be relieved with pharmacologic intervention.
- Barriers to effective pain management include patient and family barriers; professional resistance; and system barriers. At the patient and family levels, concerns about addiction prevail, despite ample research evidence that addiction is rare. Patients and families have concerns about possible side effects of pain medications, fear their use, and are reluctant to report pain because of religious or cultural influences. Many believe that pain is an inevitable consequence of cancer and, therefore, do not attempt to alleviate it. These concerns are most prevalent among older, less educated, and lower-income patients and families.
- Health care professionals lack adequate knowledge of pain assessment and management techniques. Concerns about regulation of controlled substances and addiction serve as

barriers to adequate pain control. With heightened emphasis on cost-effective disease management, inadequate attention is given to pain and symptom management. Individual provider bias and misconceptions about pain control approaches and late-stage hospice referrals force patients to suffer needlessly.

- System barriers to pain management include a lack of resources for palliative care, in general, and pain management, specifically. Most cancer resources are allocated for curative care. State and Federal controlled substance regulations influence prescribing practices. In some States, nurse practitioners, including oncology nurse practitioners, are prohibited from prescribing narcotics. This situation constrains their ability to provide adequate pain control.
- Many insurance companies do not provide adequate reimbursement for costly oral and transdermal analgesics. Out-of-pocket costs for these drugs can range from \$100 to \$200 per week. Opioid availability may be limited, particularly in nonwhite neighborhoods. A recent study showed that only 25 percent of surveyed pharmacies in nonwhite neighborhoods had enough opioids to treat severe cancer pain, compared with 72 percent of surveyed pharmacies in white neighborhoods.
- The lack of palliative care services and fragmentation of cancer care are major issues. High-technology palliative care, including radiation and chemotherapy, is quite expensive and not being reimbursed adequately. Most palliative care, however, is not expensive.
- There tends to be a lack of Advanced Care Planning, particularly among patients treated in outpatient settings. Intervals between appointments are sometimes lengthy, and continuity of care may be inadequate. As a result, communication with the patient about symptoms is insufficient, and patient needs may fail to be addressed adequately.
- With the exception of Medicare, third-party payer reimbursement practices limit palliative care delivery by nurse practitioners.
- Nursing homes in Wisconsin are experiencing considerable financial distress because third-party payments, particularly Medicare, do not cover the cost of care. Over 10 percent of Wisconsin's nursing homes have filed for bankruptcy in the past 18 months.
- Drug reimbursement may be insufficient for pain and symptom management. Patients report taking less nausea and pain medication than prescribed, or extending the time between doses, because their medication is so expensive.
- Wisconsin has been a leader in innovative educational and clinical programs for pain management, Advanced Care Planning, and end-of-life care. However, information dissemination and coordination among the projects has been lacking. Other problems include insufficient minority representation in current programs, inadequate reimbursement for symptom management, a lack of funding for project expansion, and a lack of sufficient programs for family caregivers.
- One of the greatest barriers to better hospice care is "having the conversation" with families about the need for hospice.
- The Wisconsin Pain Initiative was the first State cancer pain initiative in the U.S. and continues to influence decisionmaking and programs nationwide. The University of Wisconsin School of Medicine developed pain standards adopted by the Joint Commission on Accreditation of Health Organizations (JCAHO). Pain is now referred to as the "fifth vital sign." Efforts are underway to modify State, Federal, and international policies, laws, and regulations regarding the use and availability of opioid analgesics.

- Through a major initiative in LaCrosse, Wisconsin, more than 300 Advanced Care Planning facilitators have been trained and are now available to all health care facilities in that region of the State. Advanced Care Planning policies have been developed, and 85 percent of people in that community have now prepared advanced directives.
- Life Planning 2000 is a statewide initiative to educate and guide consumers in Advanced Care Planning. The program is a collaborative effort between the Wisconsin Bar Association, the State Medical Society, the Wisconsin Health Association, and the Gunderson Medical Center.
- The Wisconsin Coalition to Improve Palliative Care has been active in stimulating community action, provider education, and organizational change. It has developed palliative care workshops, developed statewide resource listings, participated in public forums to stimulate open discussion of end-of-life issues, and conducted a statewide palliative care needs assessment.
- The Witness Project has recently been established in Wisconsin. It is a faith-based community project for African-American women that relies heavily on African-American role models.

### **Recommendations**

- Educational programs must be developed to proactively address barriers to cancer pain control. Nurses should play a key role in the educational process and should be central to the pain management process.
- All third-party payers should reimburse nurse practitioners for cancer symptom management, regardless of the care setting.
- Uniform prescribing privileges should be instituted in every State to include Level II narcotics, and all nurse practitioners, especially those who practice in a collaborative oncology program, should have hospital privileges to ensure continuity of care.
- Palliative care must be fully integrated into routine cancer care. This includes creating a shared vision between health care providers and insurers regarding the value of palliative care. Additional resources should be allocated to pain and symptom management and relief, psychosocial support, patient and family education, and bereavement programs.
- Public and private third-party payers must eliminate financial disincentives to earlier referrals to hospice and other home care systems. Benefits should include nurse-coordinated managed care. Oral and transdermal analgesics should be reimbursed and the costly copayments eliminated. Medicare and Medicaid home care coverage should be expanded to enable patients to be cared for at home longer.
- Outcomes research must be conducted to provide evidence of the cost-effectiveness of adequate cancer pain control programs. A recent study demonstrated that the cost of readmissions for uncontrolled pain was more than \$5 million in 1 year for one institution. After initiating a simple and inexpensive pain management program, the readmission rate fell, resulting in a savings of more than \$2 million.
- Additional palliative care research must be undertaken to examine the effectiveness of interventions provided during the terminal phase of cancer, the mental health issues experienced by the patient and caregiver, and the economic hardships resulting from the lack of reimbursement for palliative care services.

## MR. ROBERT SPEER

### Key Points

- One of every three women and one of every two men will be diagnosed with cancer in their lifetime. More Americans have died from cancer in the past year than died in all the wars of the last 100 years. Every 60 seconds, an American dies of cancer, and every year, 1.2 million are diagnosed with the disease. We are constantly reminded of the devastating impact of cancer. Fear of cancer and its treatment is so pervasive that many fail to seek care until it is too late. Research indicates that cancer is the most feared disease in America.
- Mr. Speer recounted a case of a postmenopausal woman who ignored serious vaginal bleeding for 3 years. Because she was so afraid of the possibility that she might have cancer, she avoided contact with the health care system. Her failure to act was not due to a lack of information or education, but rather a reflection of her pervasive and paralyzing fear of the disease.
- Fear of cancer drives people to desperate and sometimes harmful measures. People often obtain and follow advice they receive through the Internet, or they cling to simplistic explanations of their medical condition. Frantic pursuit of unfounded cures becomes a distraction that can cause costly delays in receiving effective treatment and, ultimately, can mean the difference between life and death. Fear often evokes denial. Risk factors are ignored or misconstrued, leading people to believe that they are not at risk for cancer.
- There is a significant psychological distance people must travel in order to get care. Health facilities may unwittingly reinforce people's fears of cancer. For example, many facilities have a prominent piece of artwork in the lobby memorializing all of the people treated at the facility who died. Similarly, rallies often emphasize those lost to cancer, rather than those who survive. In contrast, Covenant Healthcare developed a program titled *Beyond Cancer* to decrease the level of fear associated with the disease. The program began with poster-sized photographs of cancer survivors coupled with powerful stories of how they battled the disease and then moved on with their lives. Their stories have been replicated in a small booklet that can be found in numerous clinical areas of the facility. The booklets provide a sense of hope to patients and their families throughout the treatment process. Covenant Healthcare encourages other facilities and programs to copy and use the booklet.
- Local community representatives should be directly involved in planning, publicizing, and implementing cancer screening programs. This establishes trust in the community and helps ensure that the program has sufficient credibility to warrant public participation. Covenant Healthcare put these principles into practice in developing a prostate cancer screening program for African-American males. In designing the program, Covenant partnered with local African-American organizations to publicize the event; enlisted a popular African-American radio personality to provide radio coverage; selected an African-American urologist to speak at the event; and advertised the program through the local African-American newspaper. In addition, the well-known African American director of the Emergency Department connected with local churches and other organizations to promote the event. As a result of these combined efforts, participation was five times the level achieved in previous screening efforts.

### Recommendations

- Stories of cancer survivors should be prominently featured wherever possible. People need to understand and believe that a diagnosis of cancer is not an automatic death sentence, and if

cancer is detected early and treated properly, survival is possible. If the public hears messages of hope, it may more readily participate in early detection efforts and obtain treatment more quickly.

- Programs should be developed and promoted that are sensitive to the psychosocial needs of newly diagnosed patients and their families. These programs must be designed to address the cultural barriers that often impact prevention and early detection programs.
- Policymakers need to ensure that people whose cancer is detected through screening have access to appropriate treatment.

## **DISCUSSION—STATE OF WISCONSIN**

### **Key Points**

- Funding should be provided to indigenous, community-based organizations directly, not just to major public and private institutions. There needs to be a commitment to capacity-building in the communities that are most affected by cancer. Cancer is much more than a medical disease, it is a human condition. Anything that improves the quality of life in affected communities should be undertaken. Providing funding to community-based organizations not only results in more effective programs (particularly in the area of outreach), but it also fosters increased local employment, which ultimately improves quality of life.
- Identifying legitimate community-based organizations for potential cancer-related grant funding can be difficult. One approach to this problem would be for the Federal or State Government to release a formal Request for Information to identify potential grant recipients. Organizations could be required to describe all relevant aspects of their operations and provide documentation of their roles as key players in their respective communities. In addition, prerequisites for participation can be established, such as requiring the organization to have established links to State or local health department programs.
- It also may be difficult for smaller organizations to provide the infrastructure necessary to carry out activities of some of the major grant initiatives. Because the larger organizations tend to have this infrastructure in place, they tend to continue receiving the bulk of available funds. The Federal Government should consider funding capacity-building activities in smaller community-based organizations. If sufficient infrastructure is developed with the seed money, those organizations could then be eligible to compete for the funding associated with program implementation.
- Large institutions such as universities and health departments are not held sufficiently accountable for their performance under grant programs. Too often, excuses are made for their poor performance, and they do not suffer the consequences when they apply for future funding. Yet community-based organizations that fail to perform are often barred from future efforts. All providers must be consistently held accountable.
- As an example, the Cancer Center in Madison, Wisconsin, has devoted little effort to developing organizational linkages for community outreach, despite the fact that it is an NCI grant requirement to do so.
- Communities most in need of financial support for cancer research and service delivery are less likely to receive them because they are inexperienced in the complexities of grant writing; they lack the necessary infrastructure and are unprepared to conduct scientific followup. Funding patterns have become entrenched, often leaving community-based

organizations (which are likely to have the most positive impact on the community) out of the picture.

- The best way to encourage or motivate people to participate in cancer screening is to develop ongoing, established relationships with local providers. These relationships are most effective when cultivated on a one-to-one basis. When the only contact with the provider occurs when a problem is detected, the provider becomes negatively associated with the problem. This association thwarts prevention and screening efforts.
- People need to become accustomed to thinking about their health on a daily basis, rather than just when illness strikes. Health education/prevention materials should be considered a secondary source of information, not a substitute for face-to-face contact. Personal contact with community members around health issues (e.g., health ministries established by churches) can disseminate messages (e.g., more healthful cooking techniques) far better than pamphlets. This relational approach is time-consuming, but effective.
- Being poor does not automatically mean that one is unable to manage one's own life. In fact, many extremely poor people are finding ways not just to survive, but to thrive and provide supportive environments for their families. The effects of poverty should not be minimized, but it must be recognized that poor people become extremely adept at navigating through society to maximize opportunities. Because of their demonstrated resiliency, they can be very effective in building trust in the community and motivating others to take control of their lives, including their health.
- While some access and discrimination issues are common to African Americans regardless of income or education, strategies for working with the African-American population on health issues may need to differ depending on the socioeconomic status of the target group. Poor African Americans may have almost as much trouble relating to well-educated, wealthy black people (e.g., physicians, professional athletes) as they do to whites or other non-African Americans. It is essential that the target group members believe that the person bringing the message has lived through life problems similar to their own.
- Some problems of health care access are common to all poor and underinsured people regardless of ethnicity/race, but others are related to social injustice and need to be addressed as such.
- Health-related statistics for Native Americans are either incomplete, inaccurate, or absent. As a result, there is no clear picture of how cancer impacts the Native American community and how it should be addressed. Survivorship should be promoted so that Native Americans grow more comfortable with talking about cancer and overcoming cancer-related fears and superstitions. There is also a general reluctance to provide statistics of any kind because of the belief that data-gathering will ultimately result in loss of land and forced relocation.
- It is important to note that SEER, the NCI's key cancer surveillance database, contains data for only 3 out of more than 560 tribes. These data cannot be used to develop generalizations about the Native American population overall. One also must bear in mind that the tribes have very distinct cultures and customs that must be considered in designing any type of health care program. In addition, tribes tend to be ethnocentric, which complicates efforts to have tribes work together on health or other issues.
- Although there has been increasing interest in palliative and end-of-life care, considerably greater funding and research in these areas is still needed. The bulk of health care funds for end-of-life care are spent on high technology interventions when, in reality, resources would be better used and more evenly distributed if there were greater emphasis on symptom

management at the final stage of disease. A general resistance to discussion and acceptance of mortality persists. Frank discussions about end-of-life care often are initiated far too late in the dying process. At present, there is a clear separation between active cancer treatment and palliative care. Palliative care, particularly symptom management, should be incorporated throughout the course of the disease.

- Health care training programs must be modified to include end-of-life care and pain management education. Currently, prevention and treatment are overemphasized relative to the entire spectrum of health care needs.
- Physicians often are criticized for their inattention to the psychosocial needs of cancer patients and their families. It is desirable for them to meet these needs, but perhaps not all physicians can or should have this responsibility. Physicians are struggling to keep pace with the technological developments in health care and new treatment approaches. This may leave little time to focus on the psychosocial aspects of the healing process. Palliative care and psychosocial support can perhaps be addressed better through nursing care. Physicians and nurses must develop more open communication about patients' needs and cultivate mutual respect for their roles in the care process.
- Community-based outreach is not reimbursed by Medicare, Medicaid, or other third-party payers. Consequently, much of this work is supported by philanthropic organizations. Because budgets are small, these programs often take the quickest and easiest route to performing outreach, rather than taking time to delve into the communities to learn what approaches would be most effective for each population.

#### **CLOSING REMARKS—DR. HAROLD FREEMAN**

Dr. Freeman thanked the speakers for their participation and highlighted the day's presentations. The Panel's findings will be presented in a report to the President of the United States.

I certify that this summary of the President's Cancer Panel meeting, *Improving Cancer Care For All: Real People, Real Problems: Why Don't All Americans Receive the Best Available Cancer Care?* held on October 12-13, 2000, is accurate and complete.

Certified by:

Date:

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