

DRAFT 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?

March 8-9, 2001
Albuquerque, New Mexico

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 sixth in a series of seven regional meetings to explore issues that affect the ability of communities to provide cancer care—including prevention, education/communication, diagnosis, treatment, rehabilitation, palliative, and end-of-life care—to people in the diverse neighborhoods of the Nation. This meeting brought together representatives from eight states to discuss these issues, the barriers faced at local levels, and local- and State-level efforts to address them. The State delegations 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
Frances M. Visco, J.D.
Dennis J. Slamon, M.D.

National Cancer Institute

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, President's Cancer Panel
Yvonne Andejas, M.D., Program Director, Office of Liaison Activities
Gena Love, Member, Director's Consumer Liaison Group

Speakers

Mavis A. Alleyne, Community Representative (New Mexico)
Rubén Arana, Health Outreach Coordinator, Arkansas Human Development Corporation (Arkansas)
Maritza Arce-Larreta, M.S.N., Nurse Practitioner, Clinical Coordinator, Utah Cancer Control Program, Utah Department of Health (Utah)
Joel Arvizo, Community Representative (Colorado)
Catherine Auckland, M.S.N., C.F.N.P., Certified Family Nurse Practitioner, Las Clinicas del Norte (New Mexico)
Veronica Betancourt, Community Representative (Utah)
Judith Candelaria, M.S.N., Chief, Chronic Disease Prevention and Control, New Mexico Department of Health (New Mexico)
Robin Chavez, Community Representative (Colorado)
Rosa Lilia Compadre, Ph.D., Associate Professor, Department of Pharmaceutical Sciences, College of Pharmacy, University of Arkansas for Medical Sciences Campus (Arkansas)
Jane Cotner, M.S., Program Manager, Chronic Disease Prevention and Control, New Mexico Department of Health (New Mexico)

Catherine Danielson, Community Representative (Arizona)
 Jaime de la Isla, Community Representative (Texas)
 Cindy Deville, Community Representative (Louisiana)
 Timothy J. Flood, M.D., Medical Director, Arizona Department of Health Services (Arizona)
 Pat Graham-Casey, Executive Director, Cancer Consortium of El Paso, Inc. (Texas)
 Norma Guerra, Mariposa Community Health Center, *Platicamos Salud* (Arizona)
 Jimmy Guidry, M.D., Medical Director/State Health Officer, Department of Health and Hospitals, State of Louisiana (Louisiana)
 James W. Hampton, M.D., Medical Director, Troy and Dollie Smith Cancer Center, Integris Baptist Medical Center (Oklahoma)
 Alan A. Hébert, Community Representative (Louisiana)
 Carla J. Herman, M.D., M.P.H., Chief, Division of Geriatrics, Department of Internal Medicine, University of New Mexico (New Mexico)
 Deborah D. Hood, M.B.A., Director, Penrose Cancer Center (Colorado)
 Bruce Ignacio, Community Health Advocate, Uintah and Ouray Ute Tribe of Utah (Utah)
 Jillian Jacobellis, Ph.D., M.S., Health Promotion and Disease Prevention Division Director, Colorado Department of Public Health and Environment (Colorado)
 Mickey L. Jacobs, M.S.H.P., Executive Director, Texas Cancer Council (Texas)
 Jennie R. Joe, Ph.D., M.P.H., Professor, Family and Community Medicine, and Director, Native American Research and Training Center, University of Arizona (Arizona)
 Annie Mary Johnson, Community Representative (Texas)
 Khari La Marca, Research Associate, Native American Cancer Research Corporation (Colorado)
 Noah W. Lewis, Community Representative (Louisiana)
 Ruth S. Loisel, Community Representative (Arizona)
 Debra Long, Community Representative (Texas)
 Mary P. Lovato, Pueblo Director, A Gathering of Cancer Support (New Mexico)
 Eleanor McDaniel, Community Representative (Oklahoma)
 Edna L. Michels, Community Representative (Colorado)
 Catherine Moore, Community Representative (Arkansas)
 Christine Patterson, M.S.W., L.C.S.W., Director, Strategic Planning and Office of Minority Health, Arkansas Department of Health (Arkansas)
 Jody Pelusi, F.N.P., A.O.C.N., Ph.D. SPN Grant Coordinator, Phoenix Indian Medical Center (Arizona)
 William “Budd” Phillips, Community Representative (Oklahoma)
 Julien Puzey, M.A., Advocacy and Spirituality Coordinator, Cancer Wellness House (Utah)
 Christine Ramos, Community Representative (New Mexico)
 Walter Rayford, M.D., Ph.D., Assistant Professor of Urology, Director of Urologic Oncology Research, LSU Health Sciences Center, Department of Urology (Louisiana)
 Kathryn Rowley, R.T.T., Program Director, Utah Cancer Control Program, Utah Department of Health (Utah)
 Dana and Mark Tanner, Community Representatives (Arkansas)
 Jaquetta Tutor, Community Representative (Utah)
 Nathaniel Walker, Community Representative (Oklahoma)
 Nancy S. Weiss, Ph.D., Director, Texas Cancer Registry, Texas Department of Health (Texas)
 Donna L. Williams, M.S., M.P.H., Cancer Control Officer, Louisiana Cancer and Lung Trust Fund Board, Stanley Scott Cancer Center, Louisiana State University Health Science Center (Louisiana)
 Adeline Yerkes, R.N., M.P.H., Chief, Chronic Disease Service, Oklahoma State Department of Health (Oklahoma)

MARCH 8, 2001

OPENING REMARKS—DR. HAROLD P. FREEMAN, CHAIRMAN

In opening the meeting, Dr. Freeman noted that:

- This series of meetings grew out of the Panel's 1999 evaluation of the National Cancer Program, which identified a significant disconnect between research discoveries and the delivery of the benefits of this knowledge to the American people. The Panel concluded that the unequal burden of cancer on the poor, certain ethnic minorities, and the underserved must be relieved.
- The previous meetings in this series have been held in Omaha, Nebraska; Burlington, Vermont; Billings, Montana; Nashville, Tennessee; and Los Angeles, California. A final meeting will be held in Washington, DC. The process will culminate in a report to the President of the United States near the end of this year.
- This meeting will include testimony from the States of New Mexico, Colorado, Arkansas, Arizona, Louisiana, Oklahoma, Texas, and Utah. In addition, an evening Town Hall will provide an opportunity for the public to present questions and comments to the Panel.

**REMARKS—MS. GENA LOVE, DIRECTOR'S CONSUMER LIAISON GROUP,
NATIONAL CANCER INSTITUTE**

Ms. Love, a New Mexico native, welcomed the participants and indicated that:

- She is a cancer survivor; caregiver to her parents, who are also survivors; and Director of Support Services for New Mexico's oldest and largest grassroots survivorship organization, People Living Through Cancer (PLTC). In addition, for the past 4 years, she has served with NCI's Director's Consumer Liaison Group (DCLG).
- Relatively early in his tenure at NCI, Director Dr. Richard Klausner saw the need to enrich the cancer research effort by involving in the national cancer agenda people who have been affected by the disease. The original 15 members of the DCLG were chosen from among about 200 applicants after a broad-based solicitation for applications. The DCLG represents an extensive geographic base, is ethnically diverse, and represents many facets of the cancer experience. The members are all intimately involved with cancer.
- DCLG members assist in developing a mechanism to increase consumer involvement at all levels of the Institute, meet regularly with scientists and policymakers, address key issues in cancer research, and establish and maintain strong collaborations between the Institute and the cancer advocacy community. The NCI has been welcoming and supportive of these activities.
- Serving on the DCLG requires a significant commitment of time; the group meets twice annually in Washington in addition to conducting work via teleconferences and *ad hoc* working groups. All of these activities require substantial preparation and followup work.
- Serving on the DCLG offers an opportunity to make a difference and to make heard the voices of cancer constituencies. Individuals interested in applying for membership can call 301-594-3194 or visit liaison@od.nci.nih.gov. The application process will open again in October 2001, when five new members will be chosen.
- The DCLG became a federally chartered committee in 1998. Its working groups have been involved in developing the *Genetics Primer*, endeavoring to establish a central Institutional Review Board (IRB), and providing input on the Bypass Budget and on communication opportunities. In addition, the DCLG has performed a number of reviews and has recently focused on health disparities in

cancer care quality, an activity chaired by Ms. Love. In all of these efforts, group members work in close collaboration with NCI staff.

- NCI formed the DCLG to ensure that those who experience the burden of cancer also help shape the course of NCI's efforts to eradicate the disease. Ms. Love noted that her experience serving on the DCLG has been among the most rewarding opportunities of her life. It has enabled her to connect with the advocacy community across the Nation and enriched her ability to serve her local constituency.

DIRECTOR'S REPORT—DR. YVONNE ANDEJESKI, OFFICE OF LIAISON ACTIVITIES, NATIONAL CANCER INSTITUTE

Representing Dr. Richard Klausner, Director, NCI, Dr. Andejaski stated that:

Key Points

- Many people know little about NCI. It is the Nation's premier cancer research agency, with a budget of \$3.3 billion. It is every person's source for state-of-the-art, valid information about cancer, through the Cancer Information Service (1-800-4-CANCER) and on the Web at *cancer.gov*.
- NCI has been including advocates in its activities, programs, and functions for about 10 years. This inclusion was previously informal but was formalized through the DCLG. Advocates improve NCI's programs by ensuring focus on patients and patient populations when research activities or research information dissemination are being discussed and planned. Advocates help focus the agenda and set priorities. They question the *status quo*, which is important in enriching research. By working with scientists and other program people, advocates also learn more about science and scientists. Likewise, scientists learn more about advocates. This interaction bridges what often has been a wide gap and ultimately improves information dissemination to the public.
- NCI has initiated a new program to further involve advocates: the Consumer Advocates in Research and Related Activities (CARRA) network. Distinct from the DCLG, which has a policy focus, CARRA will involve at least 150 consumer advocates from across the country to work on a wide range of programs and activities. To qualify as a CARRA member, a person must be one of three things: a cancer survivor, a first-degree family member, or an individual with 3 or more years' experience in cancer-related organizations. A prospective member should also be able to represent the perspective of a group—a factor that has proven important to effective interactions between scientists and advocates. In addition, one must have an interest in science and understand English.
- NCI wants to ensure that CARRA members represent the diversity of cancers and of the cancer advocacy community, in terms of disease site, urban/rural perspectives, and patient needs.
- The application package also asks for the applicant's interest in science, communication, education, general/disease-specific advocacy, and other special interests so that members can best be matched with specific NCI activities. Activities may include providing input on research priorities, identifying research gaps, and developing and reviewing information for dissemination to special populations or the general public.
- NCI recognizes the importance of supporting both CARRA network members and NCI staff through appropriate orientation activities and by clearly communicating roles and expectations. While consumers are not being invited to be scientists, they are being asked to provide the perspectives of their groups as lay representatives.
- Applications must be postmarked by April 16, 2001.

STATE OF NEW MEXICO

Presenters:

Ms. Judith Candelaria

Ms. Jane Cotner

Dr. Carla Herman

Ms. Catherine Auckland

Ms. Mary Lovato

Ms. Christine Ramos

Ms. Mavis Alleyne

MS. JUDITH CANDELARIA

MS. JANE COTNER

Background

New Mexico's population is diverse; it is considered a tricultural State. The population is 43 percent Caucasian, 42 percent Hispanic, 12 percent Native American, 2 percent African-American, and 1 percent other races/ethnicities. In addition, the population is diverse in terms of age, with 70 percent of the non-Hispanic white population over age 25, but around 50 percent of Hispanics, African Americans, and Native Americans under age 25. This diversity creates challenges for program planning and in meeting the population's health needs. The total population numbers 1.7 million. New Mexico, the seventh largest State in the Nation, is largely a rural and frontier State. One-third of the population lives in Albuquerque, and only 7 cities in the State have populations greater than 30,000.

Each year, 6,000 residents are newly diagnosed with cancer, and 2,700 die from the disease. Among men, prostate cancer is the most common diagnosis; for women, breast cancer is most common. However, cancer rates and sites vary among racial and ethnic groups. Overall, non-Hispanic whites have higher cancer incidence and mortality than other populations in the State.

Over the past year, the New Mexico Department of Health has been working with diverse partners throughout the State to revise its cancer control plan. Five goals have been established: to increase early detection and appropriate screening; increase access to appropriate treatment and care; improve the quality of life for people living with cancer and for their families; and improve coordination and collaboration among cancer control efforts. These goals will be supported by specific strategies with achievable objectives, and the plan will include recommendations for both policy and research. The plan is expected to be completed in the spring of 2002 for publication in the summer.

Key Points

- Currently, most cancer activities in the State focus on the federally funded Breast and Cervical Cancer Screening Program. The program serves women over age 50, with incomes below 250 percent of the poverty level, who live in rural areas, are minorities, and are in need of screening. The legislature is now considering whether to appropriate funds to provide for breast and cervical cancer treatment under Medicaid for women diagnosed through the screening program. Volunteer fundraising activities currently help provide treatment for diagnosed women.
- The screening program operates through Memoranda of Understanding with public health offices, primary care centers, Indian Health Service (IHS), Planned Parenthood, and private providers. Since Program inception in 1991, more than 80,000 mammograms have been performed, and almost 134,000 Pap smears have been provided to more than 97,000 enrolled women. Some research has

shown that the screening effort has resulted in earlier diagnosis among this population compared with non-program participants.

- Activities related to prostate, skin, and colorectal cancer are funded by the State and include public and professional education, outreach, and support.
- Cancer survivor support is provided through contracts with local agencies and support associations. State funds also support a contract with *Casa Esperanza*, which provides low-cost housing for cancer patients and their families who come to Albuquerque for treatment.
- Several cancer handbooks have been developed through a contractual relationship with the University of New Mexico Health Sciences Center.
- Funds will be needed to enable implementation of the State cancer plan. Funding currently is lacking for primary prevention (e.g., physical activity and nutrition). Some Tobacco Settlement funding is available for tobacco use prevention and control programs; these funds are expected to increase annually.
- The State infrastructure of equipment and providers needs strengthening; for example, current capacity is insufficient to provide mammograms to all women who should be screened. Provider retention is a problem due to several factors, including low reimbursement rates and high taxes.
- The majority of New Mexican children with cancer have access to clinical trials, but only about 5 percent of adults with cancer participate in trials. Some go outside the State to access trials.

DR. CARLA HERMAN

Key Points

- Eighty percent of cancers occur in people over age 55. Fortunately, available treatments are often as effective for older patients as for younger ones. Older patients are now being enrolled in clinical trials, and therapies are now less toxic than previously. However, older patients tend to have more comorbid conditions than younger patients, which can make access to cancer care services more challenging, since some chronic conditions result in disability.
- The CDC has just published a report on the prevalence of disabilities among adults in 1999. Overall, the disability rate was 24 percent among women and 20 percent among men. Most of the disabled population is over age 65. Thirteen percent of the older population has difficulties with activities of daily living (e.g., eating, dressing, bathing). Fifteen percent of those over age 65 reported difficulty in getting around outside the house without assistance. Thus, many older adults need help getting to the doctor and to treatments. Distance and transportation barriers common in rural states exacerbate these problems.
- New Mexico's population is diverse in terms of age and race, with few younger people among the non-Hispanic white population, but substantial proportions of younger adults and children among the Hispanic and Native American populations. Recognizing that cancer will become more prevalent in the Hispanic and Native American populations as they age, the State is challenged to plan for their health care needs.
- Better palliative and end-of-life care is needed for the older population, including control of pain, symptoms, and psychological suffering. Patients should have seamless access to palliative interventions, and geographic, cultural, and financial obstacles to good end-of-life care must be removed. An evidence-based body of knowledge must be taught to physicians, nurses, and others who provide care to patients of all ages, but particularly to ensure that older patients receive the highest-quality comprehensive palliative care. Education about palliative and end-of-life issues should also be provided to patients and their families.

MS. CATHERINE AUCKLAND

Background

Ms. Auckland, an oncology nurse for 11 years, is a family nurse practitioner with *Las Clinicas del Norte*, an organization of three clinics in Northern New Mexico established in 1973. The clinics serve 10,500 people over a 2,500-square-mile area. The population is more than three-fourths Hispanic. Fifty-four percent have less than a high school education, and most of the residents are Catholic. In addition, 43 percent are uninsured; 24 percent have incomes at or below 200 percent of the poverty level; and more than three-fourths qualify for Medicare, Medicaid, or sliding fee scales. The program offers breast and cervical cancer screening (CDC-funded); a family planning program that serves both men and women and conducts cervical, testicular, and colon cancer screening in addition to family planning services; and a high-risk protocol that funds medications and specialist visits for uninsured patients who meet financial guidelines. This latter program is funded by the United Way and is limited to a benefit of \$500 per patient per year. Of those who qualify for the Breast and Cervical Cancer Screening Program, 24 percent are receiving Pap smears, and 21 percent are receiving mammograms.

No statistics are available on cancer diagnoses among men because no programs are funded to collect these data. Cancer is still being diagnosed in late stages of disease among both men and women.

Key Points

- Family nurse practitioners have an important role in helping rural populations prevent cancer and in ushering patients into appropriate treatment if they are diagnosed with cancer. Ms. Auckland's personal goals and those of her organization are to detect more cancers at an early stage, increase the rural population's utilization of cancer screening services, decrease the number of late-stage cancer diagnoses, and increase the number of people receiving state-of-the-art treatment.
- Barriers to early detection and treatment are numerous. The age group that most needs screening is the least informed about it. The current elderly population grew up with few health services and generally does not utilize screening. Health education is not a required curriculum for graduation from high school. Most of the rural population is poor and uninsured. The mammography van does not always accept Medicare or Medicaid because of poor reimbursement practices, and the van visits rural areas only once or twice a year. The distance from diagnostic facilities is 60 to 100 miles, one-way. Health care costs and primary care providers' lack of knowledge about screening guidelines also create barriers to appropriate care. Moreover, much of the population has no primary care providers who focus on screening and prevention. Uninsured women who want mammograms cannot afford them. The screening program does not cover treatment if cancer is diagnosed. No screening program exists for males.
- Cultural beliefs also hamper early detection and treatment. These include fear of cancer and the cost of treatment, lack of knowledge about the value of detecting cancer early, and a belief among the elderly that having examinations is the same as exposing oneself.
- Options and possible solutions for addressing these problems include increasing the number of insured people, increasing funding to mobile diagnostic services and improving Medicare/Medicaid reimbursement practices, establishing screening for males, making health education part of the required high school curriculum, and improving primary care providers' cultural sensitivity and knowledge regarding screening guidelines. Health education is very important, particularly in schools; school-based clinics are very effective.
- The mammography and bone-density screening vans are very popular with rural residents. These programs provide not only services, but also coordinators (usually local residents) who are extremely

effective in persuading women to come in for screening because they have established personal relationships.

- Better training, pay, and incentives are needed to attract more culturally sensitive primary care providers to rural areas, and funding is needed for cancer diagnosis and treatment.

MS. MARY LOVATO

Background

Ms. Lovato is a 14-year survivor of leukemia and a bone marrow transplant. In 1997, she started A Gathering of Cancer Support, a support group for residents of the Santo Domingo Pueblo.

When she was first diagnosed, she tried to deny that she was ill. She knew little about leukemia at the time, but her physician explained the disease and her treatment options, which included bone marrow transplant. She agreed to the treatment.

A single parent of three small children, Ms. Lovato worried that her children would be orphaned, as she and her siblings had been. She also thought at first that her leukemia was a punishment from God for being divorced.

Following her bone marrow transplant, Ms. Lovato was in a coma for several days. She indicated that while in the coma, she saw her parents, who told her that she had a responsibility to fulfill in her tribe. After returning home, and following the required period of isolation to reduce her chance of infection, Ms. Lovato started her cancer support group. For the first 3 years, the group had no funding. Ms. Lovato was assisted in securing funding by Cathy Logan (People Living With Cancer).

Ms. Lovato's brother recently died from bladder cancer. Although his doctors allowed him to remain in the hospital, the IHS denied approval for the medication he needed. Ms. Lovato believes her brother died earlier than he might otherwise have because of this denial of care.

Key Points

- Native Americans on the pueblo are not receiving quality cancer care, most likely due to its cost. For example, women diagnosed with breast cancer are not offered tamoxifen or reconstructive surgery, nor are cancer patients offered clinical trials as a treatment option. Upon diagnosis, they are told by IHS doctors to go home and let the disease take its course. Ms. Lovato has been advocating for pueblo cancer patients to help them get the most appropriate care.

MS. CHRISTINE RAMOS

Background

Ms. Ramos, a single mother of two, was diagnosed with breast cancer at age 37. At the time of her diagnosis, she was a full-time radiologic technologist in Albuquerque, though she had no insurance through her employer.

In October 1994, a local hospital was offering low-cost mammograms. Ms. Ramos decided she should take advantage of this opportunity since she recalled a poster recommending a baseline mammogram at age 36 or older. She had no family history of breast cancer and was not unduly concerned about the disease. However, the mammogram showed a mass that ultrasound confirmed to be a tumor. The tumor was removed and found to be malignant, and the surgeon indicated that she needed further surgery. Her radiation oncologist suggested she have a mastectomy instead of lumpectomy and radiation. Having been

given little information about her disease or treatment options, Ms. Ramos was aghast that so extreme a treatment was being recommended.

Despite the state of her health, Ms. Ramos had to find health insurance to pay for her upcoming treatment. A patient advocate at the hospital helped her apply for Social Security benefits, but she had been in college and was denied because she had not worked long enough to qualify. She then applied for Supplemental Security Income (SSI) but was denied because she had not had the disease for over 12 months.

Ms. Ramos sought assistance from a legal aid society, which helped her appeal the SSI decision. During the appeal process, the judge indicated that she had been denied because she was not terminally ill. Her medical oncologist, not understanding the difference between SSI and welfare, submitted a letter saying he did not want Ms. Ramos to be on welfare for the rest of her life. Ms. Ramos believes she was stereotyped as a single mother trying to take advantage of the system, and that people with such attitudes make it hard for people in need to get help.

Enduring another degrading application process, Ms. Ramos was finally able to qualify for Aid to Families with Dependent Children (AFDC), though she was required to sell her car in order to qualify. She was at last able to begin her chemotherapy and radiation treatments.

Despite the obstacles she faced, Ms. Ramos counts herself as one of the lucky cancer patients. She noted that when she was diagnosed, she feared that she and her children would become homeless because she would be unable to pay her share of living expenses in the house she shared with another woman. However, her roommate not only understood and accommodated her financial situation, but she helped Ms. Ramos with childcare and getting to and from treatment and has been a staunch ally. Ms. Ramos further expressed appreciation for all the help she received from the hospital and anesthesiologist, who wrote off her bill entirely, and the surgeon, who reduced her fees and allowed Ms. Ramos to pay the balance as she was able over time.

Key Points

- According to SSI, a disability is defined as: “The inability to do any substantial painful activity, by reason of any medically determinable physical or mental impairment, that can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”
- Two other New Mexico residents, both in their twenties, were unable to receive medical coverage for needed care because of the 2-year waiting period for Medicare coverage of disabled persons. One of these people was too sick to undergo treatment by the time he was approved for Medicare; he died the same month in which he was approved. The other still needs a bone marrow transplant. This waiting period was to have been eliminated at the beginning of 2001 but may still be in force.
- Though she was eventually able to receive the care she needed, Ms. Ramos was forced to beg for help; people should not have to sacrifice their dignity to get treatment for their cancer.

MS. MAVIS ALLEYNE

Background

Ms. Alleyne’s urethral cancer went undiagnosed for 3½ years. She was having difficult and painful urination and sought medical attention. Her doctor performed many tests, including a cystoscopy, took biopsies, and referred her to her gynecologist. At that time, she was determined to have thickening of the urethra, which the gynecologist had not noticed in the past. Ms. Alleyne’s symptoms continued to worsen.

In the interim, her gynecologist retired, so she found a new doctor and told him of her complaint. That doctor almost insisted that she must have had a sexually transmitted disease (STD) in her younger life, because a thickened urethra is usually a result of having had gonorrhea or syphilis. Another gynecologist was consulted, and more testing and biopsies were performed. Ms. Alleyne was then diagnosed as having a urogenic bladder. Treatment for this condition produced no improvement. Her situation became so severe that she demanded further attention. She was eventually sent for an MRI scan, which revealed a large cancer that had invaded the pelvic organs.

Once the correct diagnosis had been made, the proper treatment, though difficult, was given.

Ms. Alleyne believes that the learned opinion that all black women have STDs prevented a correct diagnosis in her case. However, she does not think this was the result of racism, because she believes it was unintentional—yet the situation was affected by race.

Key Points

- Among the reasons not all Americans receive the most appropriate cancer care are: race, socioeconomic status, lack of or inadequate health insurance, fear, lack of information on illness in general and cancer in particular, lack of access to medical care, feelings of unworthiness, and past life experiences.
- Race is an issue in all interactions among people; it is more ingrained in some—including health care providers—than in others. Most of the time, those in power must be relied upon to give others what they need, so it is easy for them to withhold care as they see fit. The effect is seen among all minority peoples: blacks, Hispanics, Asians, Native Americans, and others. These people are aware of the race issue and sometimes are intimidated by it—so much so that they are hesitant to speak up for what they need or to express the feelings they have when they are sick. These are groups that usually lack money, information, and literacy, and they must rely on those in power to meet their needs.
- Language barriers are another important part of the race issue. Great apprehension is experienced when one is unable to speak the dominant language and must depend on someone else to interpret. It may cause much embarrassment when a child or neighbor must be the interpreter in personal and private matters. For the one being interpreted for, it might seem better to endure the illness than to disclose his or her problems.
- In some cultures, which may be defined by race, it is believed that cancer should not be spoken of, especially to the person with the disease. Removing this significant self-created barrier to cancer care is a very difficult undertaking.
- Because of their race and race-related life experiences, some people may feel unworthy of accepting care available to them. This may be particularly true of older people.
- People who cannot afford to go to the doctor often do not go. Even if they are having symptoms, they try to use home remedies in the hope that the condition will go away. They may think that if they go to the doctor, and something is found, they cannot afford the treatment, so it is pointless to go. Eventually, they will have to seek medical attention, but by then, it is too late for the care that could have helped earlier.
- Many people work every day but cannot afford health insurance because basic family needs must first be met. Some people will never be able to earn enough to pay for medical insurance.
- Many people believe that when a person reaches age 65 and has Medicare, medical needs will be met. This is not so; without supplemental insurance to cover what Medicare does not, a person cannot get needed care.

- It is good that people diagnosed with breast and cervical cancer through CDC-funded screening now have a source of funding for treatment, but the legislation covers only that program. There are many others with these diseases, and people with other types of cancer also need funding for treatment.
- Ms. Alleyne recounted the cases of two young women whose mothers had cancer. One woman's mother died because she did not have the money for treatment, and the daughter had to separate her parents because their \$900 a month combined income was too much to qualify for Medicaid. The other woman's mother had insurance, but it did not provide for intravenous chemotherapy, so she had to take oral medications. Her daughter was distraught because daily, she had to watch her mother gag on the many pills she had to take.
- Fear can keep people from going to the doctor. They need to be educated that cancer is not necessarily a death sentence and that they can be helped. Some people are so afraid of cancer treatment that they decide to leave their fate in God's hands. However, God has also given us the medical establishment, of which we must take advantage. People need to understand that it is all right with God for them to go to the doctor.
- This country has the money and the technology to provide care for people in rural areas who cannot get to the doctor. Access is crucial.

Recommendations

- Monies must be made available for treatment of cancer victims, just as it is available for victims of floods, fires, and other disasters.

DISCUSSION—STATE OF NEW MEXICO

Key Points

- Limited access to clinical trials is not unique to New Mexico, but transportation is a key factor in the State. Only certain areas of the State have oncologists who are able to provide clinical trials. Insurance coverage for the additional tests often required by trials, and for care not specifically related to the trial, is also a barrier. A bill that would address these coverage issues is now in the legislature.
- New Mexico has recently formed a cancer alliance with all the oncology providers in the Albuquerque area with the goal of increasing the number of adults enrolled in cancer clinical trials. IHS needs to be made aware of the availability of trials and encouraged to refer patients to them.
- Many populations in the State fear clinical trials and the possibility that they might become "guinea pigs." Native Americans have a particular concern about the ethics of research.
- Mobile mammography usually costs less than \$100 per test. This year, the van will be coming from southern Colorado. The people managing the van service attempt each year to contract with Medicare for reimbursement but sometimes cannot reach an agreement that covers their costs. As a result, Medicare patients sometimes cannot obtain screening through the van and must go elsewhere. The State Breast and Cervical Cancer Program covers only a specified population and does not supplement the cost of mammography for Medicare patients who might otherwise be able to use the mobile service.
- The higher overall cancer incidence and mortality of the white population in the State may be related to that population's older age compared to the Native American and Hispanic populations. American Indians, Hispanics, and African Americans do have higher rates for specific cancers. Lung and breast cancer are overwhelmingly non-Hispanic white diseases in New Mexico. The statistics presented are age-adjusted.

- Studies conducted during the 1960s indicated that the diets of Hispanics and Native Americans contained few processed foods; it was only when their diets changed substantially to include such foods that their cancer rates began to rise. However, when cancer was diagnosed in these populations, they tended to have lower survival rates because they had fewer health services available to them. In New Mexico, extended medical services are concentrated in Albuquerque, yet the State has the fourth largest land area in the Nation. Many State residents cannot access care in Albuquerque, and rural physicians lack the knowledge and equipment to provide effective cancer care.
- The issues of racial profiling and racialism are broad societal issues that must be addressed. In health care, providers and medical students must be taught that it is unacceptable to make diagnoses on the basis of race.
- Many people in the country believe that all minorities are taking advantage of assistance programs; this is not true. Most of the people in assistance programs are single parents who truly need the help.
- People facing a lethal disease should not have to undergo demeaning application and legal processes when they try to get help. Moreover, a person's total situation should be considered, and one should not have to give up all of one's assets in order to get financial help. Ms. Ramos indicated that she had fully intended to go back to work following her treatment, but that she had to remain unemployed in order to keep her medical coverage under Medicaid.
- Ms. Lovato expressed her anger with the IHS for the poor treatment that she, her family, and now her clients have received under this system. She believes that IHS would be improved significantly if it could provide physicians who are committed to providing quality care to the population rather than the temporary personnel who work in IHS facilities only to fulfill service requirements or to repay school loans.

STATE OF COLORADO

Presenters:

Dr. Jillian Jacobellis
Ms. Khari La Marca
Ms. Deborah D. Hood
Ms. Robin Chavez
Mr. Joel Arvizo
Ms. Edna Michels

DR. JILLIAN JACOBELLIS

Background

Cancer is the second leading cause of death in Colorado. The Public Health Department offers a breast and cervical screening program, but even though it is meeting its goal of serving 7,000 women, the eligible population numbers 68,000. The Colorado Central Cancer Registry has been in operation since 1968 and supports surveillance research and cancer control and prevention program development statewide.

The Comprehensive Cancer Control Program is a new program supported by CDC. It has given Colorado the ability to collaborate with multiple private and public partners, implement the State plan, provide a communication mechanism for cancer control and prevention statewide, and address disparities.

The Mammography Surveillance Program includes a database containing 800,000 mammograms performed over the past 10 years. The Health Department has used the database to address women's

screening issues and staging differences. The Tobacco Use Reduction and Prevention Program is funded at \$12.2 million annually through the Tobacco Master Settlement.

NCI funds the Greater Denver Latino Cancer Prevention and Control program that works in culturally appropriate ways with the community. For example, *Su Teatro*, a Hispanic community group, is developing “Cancer Monologues” that are presented in the different Latino communities and provide an opportunity to talk about cancer through theater.

Colorado’s cancer rates are similar to national statistics. Lung cancer incidence and mortality are falling for men, but not among women. Cervical cancer incidence rates among Hispanic women continue to be double the rate of those for non-Hispanic white women. Cervical cancer survival is lower than for other populations, even after controlling for stage at diagnosis.

Hispanic and black women in Colorado have lower breast cancer rates than non-Hispanic white women, but the disease is detected at later stages in these populations compared to white women, even in screened populations.

The State is attempting to pass legislation that would enable participation in the provisions of the Breast and Cervical Cancer Treatment Act.

Key Points

- Colorado would like to collect more treatment data through the cancer registry. As cancer treatment increasingly moves to outpatient facilities, it is becoming more difficult to collect these data.
- It has been known for some time that the poor and ethnic minorities have poorer health outcomes. However, the current minority populations will, in the aggregate, be the majority population by 2040.
- Colorado data show a significant impact of insurance status on early detection. In addition, older patients are less likely than younger patients to receive chemotherapy for treatment of colorectal cancer and less likely to receive lumpectomy and radiation for breast cancer.
- Denver has a single hospital that provides care to the indigent; this hospital has had to turn patients away due to funding shortfalls. Providers describe a nightmarish situation in which they have to haggle on behalf of patients to obtain biopsies at sliding fees or low-cost radiation for patients with advanced disease.
- Colorado’s directions for cancer prevention and control include improving data surveillance and management, supporting communities in developing local cancer prevention and control programs, improving the availability of appropriate treatment, and addressing the psychological aspects of cancer care.

MS. KHARI LA MARCA

Background

Ms. La Marca, a sociocultural medical anthropologist and health educator, is also a cancer pain survivor and a Native American with ties to the Kiowa, Apache, Choctaw, and Sioux tribes.

Key Points

- Having access, resources, knowledge of systems, and the capacity to ask the right questions still may not guarantee that one will get quality care.

- Myriad factors affect and may supersede the ability of Native Americans to get the best available cancer care. Among these factors are: lack of understanding about cancer; poverty; unavailable or inaccessible care; lack of insurance; lack of access to IHS facilities; lack of access to transportation or telephone communication; and lack of childcare during medical appointments or treatment.
- The profit motive and other business aspects of health care can cause underserved populations to become unserved populations. For example, screening facilities may refuse to schedule mammograms unless a community-based organization can guarantee enough participants to ensure the provider makes a profit. Similarly, treatment and followup are inconsistent among facilities, affecting the care patients receive. Native Americans suffer from delayed or late diagnoses and lack of pain management.
- American Indians living in Denver must travel 390 miles one way to Ignacio to obtain IHS services. In Colorado, although 43 percent of the American Indian or Alaska Native population lives in Denver, the inaccessibility of the IHS facility in the southwest corner of the State makes care inaccessible and unavailable. Many American Indian and Alaska Native cultural beliefs discourage open discussion of cancer, which contributes to cancer being prioritized as a lesser problem.
- The IHS has primary responsibility for providing services. However, in most areas of the country, IHS has no oncologists or other cancer specialists on staff. Cancer diagnosis and treatment are provided via IHS-contracted health services, the system used when followup tests and services are not available from local IHS service units.
- The IHS budget is extremely limited, and the use of available funds is prioritized. People are put on a list; when their priority number comes up, which may take a very long time, they are finally given some sort of service. This is unacceptable in America today. Early diagnosis and treatment of cancer is essential.
- Solutions to these problems need to begin in the community. Colorado has a program called Native Sisters, a grassroots navigator program that guides Native American women being screened for breast and cervical cancer. Program workers could benefit from more training and educational programs to increase their knowledge about cancer and quality-of-care issues.

Recommendations

- Increased funding and/or collaboration between partners is needed to develop culturally competent materials, education, and training programs about cancer for Native Americans of all ages. Intertribal collaborative networking opportunities are needed to encourage people to get together to talk about problems, seek solutions, and work toward infrastructure and resource development to ensure that cancer education, control, and treatment interventions are successful.
- Training opportunities are needed for Native Americans in medicine, social work, radiology, and other cancer-related fields.
- Strong, consistent relationships and partnerships are needed between providers of cancer care and cancer patients and their families. Greater opportunities are needed for Native community groups to meet health officials and to make recommendations that are practical and achievable in their communities.
- Programs should incorporate public health policies to improve American Indian/Alaska Natives' ability to access state-of-the-art cancer screening, diagnosis, and treatment. Policies must incorporate cultural uniqueness relevant to American Indian and Alaska Native communities. Barriers to participation in cancer interventions, including poverty, psychosocial barriers, and sociocultural issues, need to be addressed.

- Research and assessment are needed for culturally relevant, cancer policy-based interventions designed to address documented barriers within Native communities. Research is also needed to determine how standard cancer protocols must be modified to be culturally acceptable to Native American cancer patients and their families.
- Federal research funding is needed for studies on cancer pain, pain management, and intervention as it pertains to American Indian and Alaska Native patients. Proactive legislation is required that truly promotes pain management, and education on pain management is needed to increase public awareness about pain issues and how to get help. In addition, the availability of and reimbursement for pain medications and services must be improved, and barriers to access to good pain management must be reduced.

MS. DEBORAH D. HOOD

Key Points

- Shortages of trained health care professionals across the continuum of care are a major reason that cancer patients do not receive the high-quality care they deserve.
- The current nursing shortage can be expected to worsen as the nursing population ages and more nurses leave the workforce. The situation in oncology nursing is of special concern. Nursing in a hospital is physically demanding work, with undesirable work schedules for most of one's career. In oncology, emotional burnout is high. The level of nursing care in oncology inpatient units today is consistent with intensive care unit levels. With the number of complicated regimens involving chemotherapeutic agents and pain medications, staff consistency is the key to quality. "Floaters" and per diem employees lack the organizational commitment and the history of full-time staff. Yet the more openings a facility has, the more it is necessary to rely on this type of staffing. The danger is that regular staff then become tempted to join an agency, where they will make twice the money, work half as much, and accept only desirable shifts. This becomes a vicious cycle. In addition, with staff working at less than optimal levels, burnout and physical demands are increased, making it difficult to keep long-term employees.
- Ms. Hood noted that her 30-bed inpatient unit has had as many as 9 openings for registered nurses. She has filled 3 of these positions, but none of the new hires has an oncology nursing background, and all require on-the-job training.
- Similar problems exist with regard to the shortage of radiation therapists. This work is also physically demanding, and while there is emotional burnout among these employees, it is not as severe as among oncology nurses. Part of the shortage is due to the closing of radiation therapy training programs in the last 5 years. In November 2000, 72 accredited programs were operating in the United States. Colorado has no program, so Ms. Hood flies a student 13 times per year to Utah for training and pays all program expenses at a cost of \$25,000/year. In return, she has required the student to commit to working for 2 years at the cancer center.
- Radiation therapists receive faxes daily from other facilities that try to hire them away from their current place of employment. They command sign-on bonuses and relocation expenses. New graduates earn up to \$25 an hour and can earn twice that amount if they opt for agency or per diem work. This situation makes it difficult to contain health care costs and compromises staff consistency.
- Dosimetrists develop radiation treatment plans. These staff are in even shorter supply. They command higher salaries (as much as \$80,000 a year—double that for agency work—plus living expenses). Salary levels have escalated so quickly in the past few years that a dosimetrist hired 15 months ago by the cancer center at a then-competitive salary was recently hired away by another facility that offered \$25,000 more. Without adequate dosimetry staffing, patients wait longer from the time they are diagnosed until a treatment plan is developed to enable them to begin radiotherapy.

- These staffing problems are severe in desirable locations in the country; facilities in rural or less desirable areas have even greater problems. These staffing problems also compound the access issues faced by rural populations. The latest technology is of no use to patients without qualified staff to administer the treatments in a safe and expeditious manner. All of these problems are exacerbated by shrinking reimbursement rates.
- The vast majority of patients who utilize hospice services are cancer patients, many of whom are Medicare recipients. The structure of the Medicare hospice benefit prevents many cancer patients from taking advantage of both hospice support services and certain palliative treatments. Since it was established in 1983, the Medicare hospice benefit has not changed to reflect the many changes in end-of-life care. The current reimbursement rate in Colorado is \$102 per day, which covers all physician and nursing care, medication, and any other treatments or services given to the patient. Palliative care may include radiation therapy to relieve bone pain, medication to prevent calcium loss from bones or alleviate high blood calcium levels that cause confusion and pain, and management of anemia that causes fatigue. The cost of treatments such as these exceeds the daily reimbursement, however, so patients must choose between the treatments and hospice care.
- In addition, some of the new chemotherapeutic agents can suppress tumor growth, and patients delay hospice care in order to continue these treatments because of the relief and quality of life they provide. But by doing so, they often die within days of being admitted to hospice or die without hospice, thus being unable to avail themselves and their families of needed support. When all else has failed, we owe it to our patients to help them die with dignity and in peace.
- Genetic counseling represents a true gap between research and applied health care. A number of genes have been identified whose presence can predict the likelihood of cancer, allowing individuals to take action to increase surveillance or implement preventive measures. The most educated caregiver on this subject is the genetic counselor, but only physicians can bill for genetic counseling services. Genetic counselors can spend the time needed to appropriately assess risk and to educate and counsel a patient; physicians have neither the training nor the time to do so. Some insurance companies now cover the cost of gene testing in high-risk patients but do not cover the counseling necessary to determine if gene testing should be done.
- Genetic counseling is especially critical for young women who do not meet traditional screening criteria for mammograms, but who come from high-risk families. Through a grant from the Susan G. Komen Breast Cancer Foundation, the Penrose Cancer Center is able to provide genetic counseling. In 2000, 225 patients received counseling; that number is expected to double in 2001.

MS. ROBIN CHAVEZ

Background

Ms. Chavez was diagnosed with breast cancer in 1993, 4 months after her mother died from the disease. She underwent a mastectomy and subsequently took tamoxifen. She feels she received excellent care overall, with the exception of hospital nurses who made her feel pressured to go home quickly following surgery.

Key Points

- Ms. Chavez indicated that her mother delayed going to the doctor because she believed her breast lump would go away by itself. Ms. Chavez has encountered this attitude and the fear of diagnosis among many other women. Two of her sisters found breast lumps; Ms. Chavez had to persuade them to have these investigated. Fortunately, these lumps were benign.

- Some people do not have the means to go to the doctor and do not qualify for Medicaid, Medicare, or other assistance programs.

Recommendations

- A source of care must be established for cancer patients and those with suspected cancer who do not qualify for assistance programs but cannot afford to pay for care.

MR. JOEL ARVIZO

Background

Mr. Arvizo was diagnosed in 1998 with a brain tumor. For some time prior to that, he was mistakenly and repeatedly treated for migraine headaches. His symptoms included vomiting, nausea, blurred vision, photosensitivity, headache, and severe weight loss. He was treated in the emergency room on numerous occasions. His doctor resisted referring him for an MRI. When he finally agreed to do so, he asked if Mr. Arvizo had a credit card. Since he was uninsured, Mr. Arvizo had been paying for all of his medical care with a credit card. This drained the savings he had accumulated for his children's education.

The MRI showed a tumor in the right frontal area of Mr. Arvizo's brain. He was immediately scheduled for surgery. Later, he returned to see his surgeon, only to find she no longer worked at the hospital at which he was treated. Other doctors at the facility did not want to treat him because they did not have a contract with the insurance company that was now covering Mr. Arvizo. He finally found an oncologist who would treat him at no cost. Mr. Arvizo underwent radiation therapy, but his tumor recurred. Gamma knife treatment was unsuccessful, and he underwent another operation. He experienced complications following the surgery, which necessitated another operation and 6 weeks of intravenous antibiotics.

A year later, in 2001, an MRI showed that Mr. Arvizo's tumor appeared to be growing again. He received a PET scan, which was negative, and it was concluded that the area of concern indicated on the MRI was scar tissue.

Key Points

- Mr. Arvizo believes that he was treated differently from other patients because he was uninsured and because he was not fluent in English. He also noted the difficulty he faced explaining information about his diagnosis and treatment to his wife and parents, none of whom speaks English.
- Mr. Arvizo received books and videos about his cancer from his doctor. He indicated that he would not have known where else to get information about his disease.
- When the physicians did not want to honor his insurance, Mr. Arvizo sought financial assistance to help pay his medical bills; no one he contacted was willing to help. He eventually received a Social Security supplement of \$7,000 to \$8,000 over a 6-month period, but he is now being required to repay it, for reasons he does not understand.
- Though he is distressed that people without insurance do not get the care they need and deserve, Mr. Arvizo indicated that as a self-employed person, he understands why doctors do not want to treat people if they are not going to be paid.

MS. EDNA MICHELS

Background

Ms. Michels, a melanoma survivor, has an extremely strong family history of cancer. Her mother was one of ten children; all died of cancer. She noted that her mother's lymphoma was diagnosed when she was 60 and required multiple treatments, but that she died of melanoma 20 years later. However, because Ms. Michels' father did not believe in insurance, the family paid many thousands of dollars in cash for her mother's extensive care over this period.

Ms. Michels worked for the airline industry for many years, moving from Florida to Colorado after her mother's death. Shortly after moving to Colorado, both she and her husband lost their jobs. Her husband died from a heart attack shortly thereafter.

Ms. Michels subsequently volunteered as a subject for a number of studies at the University of Colorado Health Sciences Center. A physician there noticed a lesion on her leg, which a biopsy determined to be melanoma. Ms. Michels underwent Mohs micrographic surgery to remove the cancer.

At times, Ms. Michels had been very depressed, even suicidal, due to distress over her own and her family's cancer experiences. She now has a more philosophical outlook on her experiences.

Key Points

- A listing of pharmaceutical companies that provide free or deeply discounted medications is available at www.needymeds.com. More than 1,000 medications are listed.

DISCUSSION—STATE OF COLORADO

Key Points

- To improve the reach of the Breast and Cervical Cancer Screening Program, Colorado is designating specific rural hospitals or areas as Critical Access Hospitals or Rural Resource Shortage Areas, respectively. Such designations will facilitate getting help to rural areas to provide more comprehensive care.
- The IHS is severely underfunded. The agency does not have enough staff, and turnover is extremely high. Many doctors work in IHS facilities to fulfill medical student loan obligations and leave as soon as their term of service is over. It is difficult for communities to collaborate with the IHS to see that access and availability are more comprehensive. IHS may contract with facilities anywhere in the country; people may be diagnosed in Arizona and sent to Minnesota for care—when they get care. The time between diagnosis and treatment ranges from 6 to 12 months. In addition, because of the limited funding available for cancer care, younger patients are given priority. Native American Cancer Research is studying these issues.
- The many factors contributing to disparities in cancer outcomes among the major populations of Colorado include access to care, utilization of care, screening, poverty, and factors less easy to measure, such as alienation and isolation. The interplay of these factors is complex. Several studies in the past few years have indicated that equal treatment at the same stage of disease yields equal outcomes, suggesting that disparities are related in large part to who gets treated in a timely manner and with good care. The Colorado Health Department is putting its critical investment in cancer prevention and control into addressing these disparities.

- Sociocultural medical anthropology studies the sociologic, cultural, and medical aspects of health care as they pertain to access to and availability of care, cultural and sociocultural barriers to care, poverty, and distance. All of these aspects are important to an environmental perspective in our approach to cancer—including education; primary and secondary prevention models; ways in which people are ushered into treatment; and ways in which they are assisted to address economic, spiritual, and other issues.
- Clinical trial and other cancer treatment protocols are usually developed by beginning with the science; information is provided to everyone in the same manner. This approach seldom accommodates cultural differences. We need to start developing protocols beginning with the people and joining their concerns and differences with the science.
- People from the Native American, African-American, and [urban and rural] Hispanic communities need to be assisted—through outreach, mentorship, and financial support—to become doctors and scientists. In this way, they can bring the sociocultural understandings and healing traditions of their populations to the scientific realm.
- To solve the health care personnel shortage, more people must be encouraged to enter the health professions. Currently, most people, including high school counselors, are unaware of the many career opportunities in the health field. Many of these careers (e.g., in imaging) offer good salaries and do not require extensive education.
- Nurses have never been properly recognized for the professional services they provide. In the current health care environment, nurses are being asked to care for more and more patients, to the point that quality of care is compromised. When hospitals look for ways to cut costs, they first cut the nursing staff—usually beginning with the most experienced nurses.

STATE OF ARKANSAS

Presenters:

Ms. Christine Patterson
Mr. Rubén Arana
Dr. Rosa Lilia Compadre
Ms. Catherine Moore
Ms. Dana Tanner
Mr. Mark Tanner

MS. CHRISTINE PATTERSON

Background

Arkansas currently has the 16th highest overall cancer mortality among the 50 states and the District of Columbia. In 2000, Arkansas had 13,000 new cases of cancer and 6,200 deaths. Arkansas presently rates as one of the unhealthiest states in the Nation. Two major issues contributing to cancer—and poor health generally—in Arkansas are tobacco use and the lack of primary health care providers. In 1998, 29 percent of men and 24 percent of women in the State reported smoking. In 1997, 48 percent of white and 29 percent of black students reported that they were smoking cigarettes. The population voted to allocate all of the State's Tobacco Settlement funding to health care, but this voter mandate could be altered by State legislators.

In addition to the Breast and Cervical Cancer Screening Program, the State legislature appropriated funds to provide for treatment of detected abnormalities.

Poverty is still a major problem in the State. Twenty-three percent of the population earns less than 200 percent of the Federal poverty level. Because the State is so rural, transportation and the limited number of primary care providers are also major issues.

Key Points

- In Arkansas, minority populations are highly suspicious of clinical trials; the memory of the Tuskegee experiments is strong. In addition, patients are often frightened by the informed consent process.
- Arkansas has one statewide newspaper. Most of the cancer and other health information printed is at the grade 13 level, yet the average educational level in many communities is grade 8. Thus, much of the population cannot understand the information being provided.
- Medical professionals in the State need more continuing education opportunities. For example, the Cancer Research Center is not linked technologically to enable distance learning.
- The Internet has brought extensive health information within the reach of many people. Patients may come to the physician's office knowing more (or thinking they know more) about a given health condition than the doctor. Some people self-diagnose based on their Internet research and may not go to the doctor when they should.
- Many older people do not appreciate the value of early detection of cancer. Even if they have resources, they may not seek preventive care or screening services.
- Though the State has been relatively successful in attracting women to its Breast and Cervical Cancer Screening Program, women with detected abnormalities often fail to return for treatment; the reason for this pattern is as yet unknown.
- In Arkansas, African Americans are the largest minority group, and the Hispanic population is growing rapidly. However, few providers from these population groups are available at State health facilities and programs. The Health Department employs interpreters and has printed most of its materials in Spanish as well as in English.
- In the past 2 years, the Health Department has moved from a centralized focus in program planning and implementation to a community-focused team approach that starts by involving the community in identifying important health issues and continuing their involvement in planning.

MR. RUBÉN ARANA

Background

The Arkansas Human Development Corporation in Little Rock focuses on migrant and seasonal agricultural workers. It is funded by the Department of Labor.

Key Points

- In Arkansas, there is growing hostility toward immigrants; some public officials are proposing policies that would foster racism and cultural bias and would deny even basic health education services to immigrants.
- Although the Arkansas General Assembly passed the Breast Care Act in 1997, migrant and immigrant workers, who are mainly Hispanic, are not receiving needed services.
- Language differences hamper effective communication about cancer and other health problems; interpreters are often required. Many Latino or Hispanic workers take a family member or friend with

them to translate when they must receive health services. Questions about bowel or bladder function or concerning pain in the pelvic or genital areas can cause considerable embarrassment.

- In 1999, the Arkansas Human Development Corporation created a program called the *Promotoras de Salud* (the Health Promoters Project). Thus far, five female *promotoras* have been trained to provide basic information on public health issues in the community. They receive a stipend of \$200. Training for the *promotoras* has been provided through cooperative agreements with organizations such as the US-Mexico Health Association in El Paso.
- In Arkansas, the only Hispanics who are counted for statistical purposes are “white Hispanics.” Those who are not light-complected are not counted.

Recommendation

- In the planning of health services for Hispanics in the State, the use of Tobacco Settlement funds, and in grant writing activities, many people claim to represent the Hispanic population, yet none are Hispanic and few even speak Spanish. These people cannot hope to understand the population’s culture and health problems. Those who will be affected directly should be involved in program planning from the outset.

DR. ROSA LILIA COMPADRE

Background

The underserved in Arkansas include those with low income, no or inadequate insurance, Latino Americans, African Americans, American Indians, rural residents, non-Arkansas-born residents, and other minorities.

The Latino population is the State’s fastest growing population, due principally to migration and the higher birthrate of this younger, predominantly Catholic population. Most of this population is low income; they work in low-wage jobs such as those in chicken-packing plants; on farms; in factories; in restaurants; in retail establishments such as Wal-Mart; in yard maintenance; and in housecleaning. Few of these jobs offer health insurance, or they have only low levels of coverage. The African-American and American Indian populations share with Hispanics many of these job-related deficiencies in health insurance coverage, quality of health education, and care.

Key Points

- The Latino population has widely varied proficiency in English, and there are few Spanish-speaking health providers. Providers and medical schools underestimate the importance of bilingual Latino health care professionals. Some patients are forced to bring children to translate for them. In addition, some providers seem unaware of the risk of translation by persons with deficient medical backgrounds; this is true even for professional translators. Current translation software is inadequate. When third parties are involved in translation, the risk of compromising patient confidentiality increases, and the additional person may cause miscommunication between the provider and patient.
- To address the language barrier, some groups have offered teaching in the most basic and colloquial Spanish. This is inadequate and unacceptable, as most of these classes are being taught by people with deficient medical backgrounds.
- Awareness of the cultural differences between the Latino community and other communities varies widely. Some Latino patients perceive that the causes of disease and healing involve intricate and profound interrelationships among the soul, body, mind, environment, and conduct of the person.

Latino patients may attribute their sickness to factors such as wind, cold, humidity, bad temper, fright, love, or inappropriate behavior.

- Some Latinos are unusually modest and may have reservations about mentioning body parts, describing personal conduct, or even mentioning a condition like cancer. These attitudes can result in serious problems—for example, a patient may be unable to describe the disease for which he or she is seeking treatment. Similarly, Latino patients may have difficulty explaining the type and degree of pain they experience or the side effects or discomfort they feel.
- Some patients also may be apprehensive or nervous about the equipment and settings of the medical facilities. They may believe cancer is fatal and that they will soon die. The patient's fear, combined with insensitive communication by health care providers can actually cause a patient to suffer a heart attack and die.
- Some health care personnel in Arkansas, especially those in positions of authority, believe that providing quality services to the Latino population is unfair because this population is using resources belonging to people born in the State. They may fear providing quality care to Latinos because that may encourage other Latinos to come to Arkansas. Some may feel that different levels of care should be provided to patients according to their ethnic background, nationality, or race. It has been Dr. Compadre's experience that Caucasians receive better treatment than other groups, and those born in Arkansas receive better care than those born elsewhere. Quality of care is also linked to English proficiency.
- Most Latinos in Arkansas are newcomers and do not understand the health care system. They may be unaware of basic patients' rights. Most of their information is received by word of mouth and is often distorted or delayed. Many have no transportation and limited or no insurance. They may not receive or be eligible for Workman's Compensation or disability payments. Many patients lack support during their illness; children may be forced to assume adult roles.

Recommendations

- People in Arkansas, as well as the Federal Government and community advocates, should recognize that the Latino population is a permanent and, in all likelihood, growing part of the population.
- Latinos should be encouraged and supported to become medical professionals in positions of authority so that they can ensure appropriate care for Latino patients.

MS. CATHERINE MOORE

Background

Ms. Moore, an Arkansas native, returned to her hometown in 1980 after living in Houston for 13 years. In 1984, she began to experience breathing problems. Her primary care physician prescribed some medication but did not order an x-ray. Three months later, Ms. Moore returned to the doctor with chest pain. An x-ray showed that she had longstanding pneumonia. She was hospitalized for 5 days. She asked to see a specialist but was told that she only needed medication. Months later, her pain returned; she was given more pills for what was described as a pulmonary disease.

Ms. Moore was ill so often that she could not work. In 1989, she began to cough up blood, and went to another physician. After another x-ray, she was sent back to her primary care physician, who prescribed more medication and told her that if she did not quit smoking, she would die of emphysema. Cancer was not mentioned. For months, she tried various products in an attempt to quit smoking. Each time she went to the doctor, she was given pills to take and sent home. In late 1999, she again became very ill, and at

that point, her lung cancer was finally diagnosed. She was told that there was no effective treatment and that she had 6 months to live.

She went to the University of Arkansas Medical Center in Little Rock and was told that although her cancer was inoperable, she could receive radiation and chemotherapy. She was told that she had had cancer for 10 years and that it had spread to her brain. When Ms. Moore's adult children spoke with the doctor about her condition, he joked that she "didn't have a chance in Hell of surviving." She was also advised that she had cause to bring a malpractice case against her primary care physician.

Ms. Moore tried without success to get assistance from the State social services agency. Eventually, her daughters found out about and enrolled her in a Medicare hospice program. She is taking medication and uses oxygen to assist her breathing.

Ms. Moore expressed her concern that she would not live to take care of her son or see her second daughter's children. She urged those with an illness to seek a second opinion and to seek specialty care if they still feel something is wrong.

MS. DANA TANNER
MR. MARK TANNER

Background

Ms. Tanner, now 40, was diagnosed with breast cancer at age 37. In 1987, she began having secretions from both breasts. Because of her family history (her maternal grandmother had died from breast cancer) and the death of a close friend from breast cancer at age 28, she was very concerned and cautious. Her obstetrician/gynecologist ordered a breast smear and a mammogram, both of which were negative. Ms. Tanner was elated and trusted that her doctor was doing everything that needed to be done. From 1987 to 1998, she returned to the doctor five times because of continued breast secretions.

During this time, she also noticed a lump in her right breast. Four mammograms performed prior to her diagnosis had all been negative. When questioned, her doctors indicated that he had no record of palpating a mass. The lump was becoming extremely painful, and Ms. Tanner consulted a breast specialist, who performed an ultrasound and recommended surgery. Ms. Tanner completed the necessary presurgical paperwork about her general health, indicating that she had heart problems, asthma, and drug allergies. During the presurgical visit, it became clear that the anesthesiologist had failed to notice any of these items on her chart. Before he left the room, to recheck Ms. Tanner's chart, the anesthesiologist suggested that she must have lied in her answers to those items. When corrected, he was embarrassed but did not apologize.

In March 1998, Ms. Tanner underwent a lumpectomy, performed by a breast specialist, on her right breast. The surgeon emphatically stated although he did not know what the mass was, she did not have cancer. Two days later, she was notified that the mass was indeed cancerous and that it had positive margins and would require further surgery. Ms. Tanner learned that a pathologist had not been on duty at the outpatient surgical center. Her confidence in this doctor was greatly shaken.

Subsequently, at the University of Arkansas Medical Center, Ms. Tanner received an MRI that indicated a mass in the left breast. It was recommended that she "watch and wait" and return in 3 months to have it rechecked. A CAT scan had revealed something on her liver, so a liver biopsy was performed. She was told that the results showed cirrhosis of the liver and hepatitis C. However, a liver specialist told her that the pathologist was being too aggressive and that she had neither disease. The official report indicated a laboratory error.

Having watched and waited for years, as recommended by her physicians and despite numerous breast smears and mammograms, Ms. Tanner discovered that her cancer had spread to her lymph system. She underwent 12 weeks of standard chemotherapy, two high-dose chemotherapy treatments with stem cell transplantation, and 6 weeks of radiation. She had no hair for almost 2 years, and her insurance company would not pay for a wig. In addition, her immune system was destroyed by the transplants, and she was told that she would have to build immunity to diseases all over again, but that she could not be reimmunized.

Mr. Tanner, speaking from the perspective of a loved one and caregiver of a person with cancer, related his feelings of betrayal and distrust following his wife's misdiagnosis. He also described incidents in which he was berated by the physician who misdiagnosed his wife because they chose to seek other care, and there were delays in crucial treatment and a life-threatening incident in which Ms. Tanner was prescribed the wrong medication and the necessary equipment and medications to revive her were not on hand.

Key Points

- Most insurance companies will not pay for an ultrasound unless an abnormality is detected on a mammogram. Most women do not know that mammography is only marginally effective in those under the age of 50 due to breast density in younger women. Ms. Tanner noted that she had had a mammogram only 7 months prior to her diagnosis. Neither of her tumors was visible on the mammogram, not even the one that could easily be palpated.
- Family members and caregivers should be able to focus their attention on their loved ones and not have to keep an eye on the medical professionals who are supposed to be attending to them.

Recommendations

- Do not tell a patient that he or she is too young for cancer.
- Do not ask a patient to watch and wait.
- Only give a diagnosis when confirmed.
- Educate insurance companies, doctors, pathologists, and patients about the limitations of mammograms, particularly for women under age 50.
- Mammograms and ultrasounds should be performed on patients under the age of 50. Cancers tend to grow faster in younger women. Early detection is a must.

DISCUSSION—STATE OF ARKANSAS

Key Points

- Improving minority participation in clinical trials is an ongoing challenge.
- It is important that cases such as Ms. Tanner's and Ms. Moore's are made public so that people understand that blind trust in physicians is misplaced. Ms. Moore indicated her belief that she was treated inadequately because she lacked health insurance. Ms. Visco expressed her hope that stories such as theirs will be disseminated. A member of a CDC evaluation group is collecting such stories to examine how community-based initiatives or projects are or should be evaluated.
- The Breast and Cervical Cancer Treatment Act provides that women diagnosed with these cancers through the CDC screening program become automatically eligible for Medicaid for all of their health

care. States need to “opt in” to this program and must provide matching funds. However, the State contribution is relatively small.

- Addressing the issue of insufficient numbers of minority and culturally sensitive providers is a challenge in the short term. Even with training of existing professionals and efforts to attract minorities into cancer care professions, it will take from 5 to 10 years to build the necessary cadre of health care professionals needed to treat minority and underserved populations effectively. Existing resources in Arkansas can be used as the core of efforts to improve culturally sensitive care; existing Latino and Spanish-speaking providers can work with the medical community and the community at large, as can existing associations such as the *promotoras*, *Centro Hispano*, and the Hispanic Health Coalition. In addition, existing radio programs in Spanish can be further utilized to address health topics. The Latino community also can further these objectives through participation in program planning and definition of key health problems.
- It was, however, suggested that the Hispanic organizations in the State have been ineffective and unwilling to intercede on behalf of the immigrant Latinos who work in the slaughterhouses and meat-packing houses. These people are being denied medical care because of antipathy toward them by the State government and the medical community.
- Some people who claim to be leaders of or to represent the Hispanic community are self-appointed; they have not been designated by the community.
- The Tuskegee experiments were one of the worst blemishes on American medical history and have been a major contributor to the distrust many communities feel regarding clinical trials. Communities need to understand that clinical trials typically compare the best available care with something that is potentially better.
- The Institute of Medicine (IOM) at the National Academy of Sciences recently issued a report saying that the health care system is broken across the board, serving no one well, and that we should no longer continue to try to fix it. Instead, a whole new system is needed, and such a system must be based on medical evidence. Lack of evidence-based medicine is a problem that crosses all economic and sociocultural situations and is an issue the Panel should address.
- People disagree about the use of the terms *Latino* and *Hispanic*. Some object to the term *Hispanic* as being a Government census designation and/or referring specifically to those descended from Spaniards. Others feel the term is more inclusive than the term *Latino*, which they believe refers only to those from Latin America. Still others believe that *Latino* includes those from Brazil, French Quebec, and people from Italy, Spain, Germany, and France who settled in Argentina. Many use the terms interchangeably.
- Dr. Slamon expressed his view that, cultural and economic problems notwithstanding, the great equalizer is cancer itself, which must be better understood from a biological perspective if we are to provide better care for all people. Dr. Freeman added his view that while a firmer understanding of the disease is crucial, it should be recognized that disease occurs under human circumstances that can have profound effects on outcome. Both disease biology and environmental/socioeconomic concerns must be addressed.

STATE OF ARIZONA

Presenters:

Dr. Timothy J. Flood

Dr. Jennie R. Joe

Dr. Jody Pelusi

Ms. Norma Guerra

Ms. Ruth Loisel

Ms. Catherine Danielson

DR. TIMOTHY J. FLOOD

Background

The Arizona Department of Health Services operates four major programs: a cancer registry, the Breast and Cervical Cancer Screening Program, the 5 A Day program, and a very large tobacco education and cessation program.

Key Points

- The shift from the hospital setting to the outpatient setting is straining the capacity of the cancer registry to do its job. Pathology reports are becoming more important as data sources; there is a need to forge closer ties with the pathology community and private doctors' offices. Requests to doctors for data are sometimes met with hostility, and this is becoming a problem. Cancer registrars and registries often function behind the scenes for most doctors and patients, and this lack of visibility has a downside of making the system seem unimportant.
- Tribal issues are extraordinarily challenging for the Arizona Health Department. Over the past decade, the Cancer Registry has forged a good relationship with the IHS and the New Mexico Tumor Registry. This relationship has resulted in the generation of highly useful data about cancers occurring among Arizona's Indians. However, as the tribes assume more of the responsibility for their own health care, this relationship will be threatened. The Arizona Cancer Registry wants to continue working collaboratively with all 21 of the State's tribes to ensure accurate tumor registration and effective use of the data. Tribal expertise in cancer and cancer registration is needed, especially in the larger tribes. Tribes also should participate in etiologic and clinical studies of cancer. It would be best for all parties concerned if the tribes were trained in, or at least knowledgeable about, cancer and cancer registration and had the capacity to recruit their own members to participate in cancer control trials.
- Cancer data can be used to target the Breast and Cervical Screening Program and direct services to areas where screening may have the greatest impact. Specific areas have been targeted by mapping late-stage diagnosis by ZIP code. For example, in the Phoenix area, seven ZIP codes have been identified in which late-stage breast cancer is diagnosed in over 35 percent of cases. Similarly, two census tracts in the southwest corner of the Tucson area have been so identified. Late-stage diagnosis is common in all of the areas occupied by the Navajo Nation, the Hopi Nation, and the other tribes living in that area of the State. This mapping is extremely useful in pinpointing observed disparities in breast cancer diagnosis and providing information needed to target screening efforts. However, although this information has been available for a year and a half, the Health Department is not using it to full advantage.
- The incidence of breast cancer in Native Americans in the Southwest is as low as the incidence in the Japanese, who have, perhaps, the lowest rates in the world. Clearly, this population is doing

something right; research is needed to find out what that is so that others can learn from them. In contrast with incidence rates, however, breast cancer stage at diagnosis tends to be later among Native American, black, and Hispanic women than among the white population.

- Cancer does not affect only the so-called minority populations. In Arizona in 1998, almost 1,000 cases of invasive melanoma and 500 cases of melanoma *in situ* were diagnosed. There is a need to educate the so-called majority (white) population that melanoma is a problem deserving attention.
- There are cancers that all groups share in common for which good screening guidelines exist and which we can do better in controlling. Notable among these are oral and colorectal cancers. We need to expand utilization of screening for these cancers.
- The State Behavioral Risk Factor Surveillance System (BRFSS) can be an important weapon in the war on cancer. Tobacco use is still the number one preventable risk factor, and efforts to reduce tobacco use must continue. It is a complex sociological and addictive problem. Media campaigns can be effective. In Arizona, the media campaign slogan is: “Tobacco—tumor-causing, teeth-staining, smelly, puking habit.” Virtually every school-age child in Arizona can recite that slogan by heart.
- More can and should be done to promote better nutrition and increased physical activity.
- It is becoming more difficult for researchers in Arizona to conduct studies. Federal regulations do not recognize the difference between etiologic studies and clinical trials.
- It is important to promote cancer prevention within managed care organizations (MCOs), which now cover most people in the West.

Recommendations

- The Arizona State Health Department should work to communicate its data better, fund and support tribal knowledge and infrastructure relative to cancer, better target high-risk groups for various cancers, promote dialogue and collaboration among all stakeholders addressing cancer in the State, and increase its role in primary prevention.

DR. JENNIE R. JOE

Background

Arizona has the third highest American Indian population in the country, behind only California and Oklahoma. The State contains 21 reservations. Most of the Native population in the State is still heavily dependent on Indian Health Service as its primary health care provider. According to the IHS annual report, approximately half of the Native population in Arizona utilizes IHS as its primary health care resource.

Cancer is the third leading cause of death in Arizona; nationally, cancer is the second leading cause of death. In Arizona, heart disease and accidents cause more deaths than cancer.

Cancer patterns differ among tribes in Arizona. Breast cancer, for example, is more common among the Navajo, whereas cervical cancer tends to be more common among the Tohono O’odham, a tribe in southern Arizona. Much of what is known about cancer in Native Americans comes from the New Mexico Tumor Registry, which is a SEER database. Additional information comes from the Arizona Cancer Registry.

Key Points

- The true burden of cancer borne by Native Americans is not known because there are insufficient data. Cancer is the second leading cause of death among Native Americans, a phenomenon that developed only over the past three decades. Native American survival from cancer is among the poorest of all ethnic minority groups. Most Native communities are not prepared for cancer. The severely underfunded health care delivery system still focuses on acute care and infectious diseases, with little emphasis on prevention and/or screening.
- The cancer data collected at the State level need to be made available to the community so that tribes can understand and make decisions about health issues. Researchers and academicians could join with the tribes and other community groups to improve communications and devise interventions that would be effective with the affected populations. Until recently, tribes have had little use for health data because they had only been the subject of studies but were never involved in identifying issues or planning for solutions.
- Racial misclassification is a problem for many tribal groups. For example, many tribal members, including those in Arizona, have Spanish surnames. Racial misclassification impacts the quality of data available.
- Despite its serious shortcomings, the IHS is the only health care available for many Native people. IHS needs more money to provide cancer care and cancer prevention programs.
- Considerable discussion is ongoing about the recent passage of the legislation to allow treatment for the uninsured and underinsured women participating in the CDC-funded Breast and Cervical Cancer Screening Programs. One paragraph of the law specifically discusses American Indians, but it is unclear whether Indian women will have access to these services if they have access to Indian Health Service and are therefore considered insured. These types of questions or concerns—i.e., whether American Indians are eligible—always come up when there is a new policy or legislative action. Such questions always seem to result in lengthy discussion, so that instead of getting programs up and working, it takes 2 or 3 years to determine if American Indians on reservations are legally eligible. This should not happen.
- Three Native communities in Arizona are participating in the National Breast and Cervical Cancer Early Detection Program. These tribal programs have to deal with many difficult issues. They are not like States, which have a lot of resources. Tribes have to come up with matching funds to operate the programs. The tribal programs have developed innovative and successful ways of addressing cultural issues, cultural sensitivity, and language barriers. These interventions offer innovative models for others to adopt or adapt.
- While the recent legislation to help pay for breast and cervical cancer treatment is very important, eligibility should begin at 300 percent of the Federal poverty level rather than 200 percent. In Arizona, a State senate bill calls for eligibility at 250 percent for Indian women. The State is to be commended for this recognition and effort.
- IHS has no oncologists on staff. There are only three major medical centers across Indian country: in Anchorage, Alaska; Gallup, New Mexico; and Phoenix, Arizona. Although they are called “Medical Centers,” they do not provide comprehensive service. A consultant/oncologist comes to the Phoenix facility once a week, seeing a very large number of patients, but ongoing oncology services are needed at these facilities. IHS needs more resources so that it can meet the population’s needs and provide quality care.
- Many Native communities across the country now have programs focusing on diabetes, because it is such a significant problem for the population. The tribes have teamed with the American Diabetes Association to lobby for increased funding for Indian Health Service’s diabetes programs. This is

something that the American Cancer Society could do to help improve cancer resources for Native Americans.

- It is important to remember that budget increases for the NCI do not always translate into better cancer care, especially for those who live in impoverished communities. While important, such increases do not always affect cancer survival and/or other burdens of cancer that are not usually addressed in basic (bench) research. Such studies and programs have to take place in the community. Resources should be made available that target local agencies or organizations that can deal with cancer and cancer prevention on the front lines, not just in clinical laboratories.

DR. JODY PELUSI

Background

Dr. Pelusi is an oncology nurse practitioner who has worked in oncology for over 25 years, providing community-based cancer outreach, screening, education, and treatment services in a variety of communities and settings. She is currently an oncology nurse practitioner and grant program coordinator for the NCI Special Populations Network grant between the University of Arizona and the Phoenix Indian Medical Center (PIMC).

Key Points

- Approaches to cancer care and cancer research must be community based because communities are unique.
- Dr. LaSalle Leffall has stated that if current knowledge of cancer prevention, control, and treatment were applied and research advances continued, cancer incidence rates could be reduced by 25 percent, and cancer mortality could be reduced by half among ethnic minorities in medically underserved populations.
- Arizona has 161 mammography facilities; 101 of these are in Maricopa County. Less than 5 percent stay open after hours (i.e., after 4:00 p.m. or on weekends). Many underserved patients cannot get to these facilities during the day. If facilities were required by the accreditation process to remain open either one night or one weekend three times a year, significantly more patients could be reached.
- Rural sites should not have to bear the additional costs of mobile mammography. Dr. Pelusi's program goes to the fields and farms where migrant workers are located and provides services on site. However, the extra travel funds needed for mobile mammography are making it almost impossible to continue the service. In addition, coordinating these services long distance is difficult. No reimbursement is available for travel or for community members who provide assistance.
- The only way to provide consistency and build trust is for all programs to be community based. People in small communities frequently ask, "Are you another one of those providers or researchers who is going to come and go with your grant?" People want consistency. Communities must be empowered through community-based research so that regardless of whether researchers come or go, their cancer screening and cancer care are continuous. This means having the community as co-researchers and coeducators.
- Rural screening should not be dependent solely on grants. Cancer does not stop, but sometimes the grants do, and so services stop. Communities then have to start all over again. Grants enable us to do many things, but we become dependent on them. A great deal of time spent writing grants could be spent providing services.
- In some counties, there is only a single provider who conducts cancer screenings and cares for patients. A mechanism is needed to enable communities to hire other health care professionals to

conduct screening, thereby reducing the burden on these physicians. The primary obstacles are medical-legal barriers (i.e., related to malpractice).

- Registry data must be used at the community level because that is the level at which decisions must be made in terms of services to be provided, resource utilization, and the focus of care relative to population ethnicities and socioeconomic status. Registrars should be shared, especially among smaller registries. In this way, these registries would have data more readily available, rather than have to wait for the State registrars to come to collect data. The Indian Health Service facility at which Dr. Pelusi works has no tumor registry. In addition, registrars must be properly trained.
- The Indian Health Service uses Tribal Consultation, which provides a model for community-based practice and research. The goal is to build trust, to have respect for each other, and to share the responsibility of health care in individual communities.
- Most screenings, other than mammography and colonoscopies, can be done anywhere. Dr. Pelusi indicated that she has conducted screening programs in churches, community centers, and in the fields. While these programs have very low overhead, they are not cost-effective in terms of the travel time required. For example, one of the areas she visits is 1 ½ hours away by car; it is one of the closer locations. Thus, 3 hours of travel are required. In addition, the clinic must be set up and torn down, usually requiring another hour. In a 10- to 12-hour day, therefore, 4 hours are spent before a single patient is seen. Health care organizations question why more patients are not being seen in a 12-hour day, but the 4 hours of travel and setup are not reimbursable. These are the key issues rural providers face.
- It is difficult to get providers to support these activities. To be successful, providers have to be connected to the communities. This requires extra time so that providers can become culturally sensitive, and so that for each community, practice is based on what the community needs, not on what the providers need.
- Collaboration time is very important (i.e., trying to get people on the phone, conference calls) and very helpful for rural people.
- Optimally, screening programs for migrant farmworkers are conducted at the beginning of the season so that if abnormalities are detected, there will be an opportunity to reach them while they are still in that locale. Services are provided in the farm buildings so that workers do not have to go to another site for care, and services are provided before and after work. Unfortunately, when services are provided through a grant, providers can offer only the services covered by the grant; this makes for fragmented care.
- Existing labor laws are sometimes at odds with what works in the community. For example, Dr. Pelusi's program depends heavily on the work of a *promotora*. The community goes to her and calls her at home. She arranges appointments and other needed services. But labor laws do not accommodate work conducted from an individual's home. This situation needs to be reviewed.
- We need to be sensitive to the process. Each community moves at a different pace, so we cannot just be time-sensitive or grant-sensitive.

Recommendations

- Cancer must be approached from a system perspective. The Phoenix Indian Medical Center has a grant to do outreach and awareness activities, but the system is not ready for the demand these activities create. Therefore, in addition to providing services, Dr. Pelusi and her colleagues are training nurses and community health representatives so that as people are diagnosed, there will be a care system for them to access.

- Many communities believe they are too small to participate in clinical trials. Many doctors do not want to take on clinical trials because they create more work for them and support is insufficient. Institutional review boards (IRBs) should be considered from a community perspective versus only through a hospital or an agency.
- It is essential that patients have a treatment plan that is written and retrievable to ensure that care will be appropriate regardless of where it is received. This is one point at which there is a disconnect in the continuity of care, including long-term followup.
- It would be helpful if tumor registrars were accompanied by a provider; data could then be entered and accessed more quickly.
- Care should be bound by commitment and concerns for the community, not by contracts.
- The need for nurses is great. Reimbursement for nursing must be revisited. Those currently in nursing school are likely to choose other professions. We need to training them for what they need—community health nursing, research community nursing, and cultural competence. The Oncology Nursing Society has developed guidelines on multicultural competence relative to education, clinical practice, and research.

MS. NORMA GUERRA

Background

Ms. Guerra is an 11-year survivor of breast cancer. She conducts breast cancer education and screening outreach, works with cancer patients, and runs a support group at the Mariposa Community Health Center in Nogales, Arizona. Nogales is a community of approximately 25,000 along the U.S.-Mexico border. Cancer incidence in the area is high.

Key Points

- Many in Nogales have only part-time employment that does not offer health benefits. These employees usually earn minimum wage and cannot afford to buy health insurance on their own, as they can barely pay for rent, food, and clothing. By offering only part-time employment with no benefits, major employers in the area, such as Wal-Mart, boost profits and growth by limiting personnel costs.
- Arizona has provided breast cancer screening funding for 10 years but still does not provide for treatment of detected abnormalities. Recently, Ms. Guerra has been approaching doctors in Tucson who might provide free care; however, hospitals are unwilling to provide needed MRI, CT, and other tests for these patients.
- Women who do not have legal status in this country often return to Mexico for cancer treatment while their families remain in the United States.
- The embarrassment associated with being treated by a male doctor is a major barrier to care, especially among older Hispanic women. Treatment for cervical and breast cancer almost always requires exposure of the body, which is prohibited by cultural and social traditions. This, combined with limited access to female doctors in Nogales creates an even greater barrier for those needing treatment. As a *promotora*, Ms. Guerra talks to women, trying to help them overcome their embarrassment. Some women, however, are so modest that they are even uncomfortable disrobing in front of their husbands.
- Specialty cancer care, including radiotherapy, is available only in Tucson, 60 miles from Nogales. This distance is a significant barrier for patients, particularly if another person must transport them

and be absent from work. The Center has a grant from the Komen Foundation to provide transportation to treatment.

- Some women are afraid that cancer treatment costs will devastate the family financially and often keep their condition secret. An important role of the *promotora* is to convince the woman that as the pillar of the household, she is needed and must get care for the sake of her family.
- Some women believe their cancer is God's will. In addition, many would rather die than have a mastectomy. They fear that they will no longer be complete women and will be rejected by their husbands.
- Lack of childcare causes some women to forgo treatment.
- Many people still believe that cancer is a death sentence and prefer not to know if they have cancer. The *promotora* addresses these types of issues as well.

MS. RUTH LOISEL

Background

Ms. Loisel is a survivor of squamous cell oral cancer. In August 1998, she was referred to an ear, nose, and throat (ENT) specialist because of a sore on the right side of her tongue and an earache. The ENT located two other lesions on her tongue and one on a vocal cord. Test results indicated that only the vocal cord lesion was benign. Ms. Loisel's only treatment choice was radiotherapy. She was referred to an oncologist in mid-October; by this time, the cancer had spread to the lymph nodes in her neck.

Before beginning therapy, however, she was told that she required extensive dental work or, alternatively, would have to have all of her teeth pulled. Having been on disability since 1987, Ms. Loisel had been unable to afford regular dental care. She was referred to an oral surgeon who would pull all her upper teeth, but would save 11 of her bottom teeth that were sound. This could not be done until mid-November, when Ms. Loisel's oncologist was able to persuade her insurance company to pay for the care, which he indicated was justified as preparatory to radiation therapy.

Ms. Loisel's radiotherapy finally began on November 30. The therapy was very painful, and only encouragement from her nurses kept her from stopping her treatments at two points in the treatment regimen.

When Ms. Loisel's insurer again refused to pay for fluoride treatments needed to save her remaining teeth, she was assisted in finding a local doctor [dentist] who would provide this care for free to cancer patients. A year after the conclusion of her radiation therapy, Ms. Loisel was cancer-free. However, her salivary glands had been destroyed by the therapy. When two of her teeth became loose, her insurer again refused to cover their extraction by an oral surgeon. Not knowing that there could be complications, she had the teeth removed by her regular dentist. She developed bone disease where the bone had been exposed as a result of the extractions.

During this time, Ms. Loisel was unable to eat and was losing weight. Her dentures could not be made to fit properly because of the bone damage resulting from her radiation therapy. She subsisted on Slim Fast[®], which she purchased because it was less expensive than Ensure[®]. However, this inadequate nutrition caused her electrolytes to become so imbalanced that she had a seizure and was delusional. She was hospitalized until she recovered.

Since Ms. Loisel's salivary glands were destroyed, she must carry and drink water constantly. Recently diagnosed with osteoradionecrosis and osteomyelitis, she is undergoing hyperbaric oxygen (HBO)

therapy that it is hoped will stop the disease and repair the bone, tissue, and other damage done by the radiotherapy.

Ms. Loisel indicated that she is becoming healthier, has regained some weight, and has an improved quality of life. She is considering writing a cookbook for oral cancer patients.

MS. CATHERINE DANIELSON

Background

Ms. Danielson, 39, is a 2-year survivor of stage IV squamous cell throat cancer and the single mother of four children. At the time of her diagnosis, she was working as a night-shift waitress in a small town in Arizona.

For 8 months, Ms. Danielson, a longtime smoker, went to a succession of doctors trying to determine the cause of symptoms that included severe weight loss, pain, difficulty swallowing, and fatigue. Since she had no insurance, she was treated only symptomatically with antibiotics and was not referred for any diagnostic testing. When she asked for medication to relieve her severe ear and jaw pain, she was accused of being drug-addicted. It was also suggested that she was overreacting, that she was simply seeking attention, and that she needed counseling. She paid cash for all of these visits, a considerable hardship for her family.

Ms. Danielson attempted to get State medical assistance, but her monthly income of \$900 to \$1,100 for a family of five exceeded the income ceiling. However, Ms. Danielson's condition continued to worsen; she could not eat, drink, or even swallow her own saliva. She made an appointment with the only ENT specialist in her town but was put on a 2-month waiting list. While she was waiting for the appointment, she took a lower-paying job (20 hours a week at \$2.50 an hour) in an attempt to qualify for medical assistance. The day before the ENT appointment, she was approved. However, she had not yet been issued her medical card, and although she offered to pay cash for the visit, the ENT's office refused to honor her appointment because she did not have either the card or a referral from her primary care physician.

She was able to get an appointment with the primary care physician 2 weeks later. This doctor called the ENT's office and indicated that Ms. Danielson needed to be seen. She was given an appointment for a date $2\frac{1}{2}$ months in the future. The primary care physician suggested she might have a neurologic disorder and sent her to a neurologist who said she needed to see an ENT. He sent her to a colleague 60 miles away who diagnosed her cancer.

By the time Ms. Danielson had emergency surgery, her tumor was so advanced that she was days away from suffocating. Her surgery was followed by intensive radiotherapy, which caused many severe and long-lasting side effects. She now speaks with the aid of a handheld device.

Since her surgery, Ms. Danielson has been living on Social Security payments and is on the 2-year waiting list for Medicare eligibility. In January 2001, she received a \$15 cost-of-living increase in her Social Security payment (from \$599 to \$614). This increase put her 66 cents over the income ceiling for the Arizona Medical Assistance Program, and her health benefits were discontinued. This occurred because of Arizona's eligibility determination system, which has not kept pace with current assessments of the poverty level. The allowable income level for adults is tied to the 1992 poverty level. Although Arizona citizens have voted to use Tobacco Settlement funds to bring the program up to date, the legislature has dragged its feet. Federal matching funds have been secured but will not be phased in until next year. Ms. Danielson noted that this may be too late for her and many other cancer survivors. Ms.

Danielson indicated that she occasionally experiences ear pain similar to the pain she had prior to her surgery and that she worries about her future.

A former smoker, Ms. Danielson attributes her cancer to her tobacco use. Since her treatment, she has appeared in an award-winning anti-tobacco public service announcement.

Key Points

- The system needs to be made consistent for everyone. People are being denied health care systematically, and dollars are at the root of these decisions. Those being excluded from the system tend to be those with few resources, regardless of race or culture.

DISCUSSION—STATE OF ARIZONA

Key Points

- Though cancer is a reportable disease in Arizona, few penalties can be levied against doctors if they do not comply. Some physicians feel it is too much of a burden to provide the patient's stage of disease and address. The importance of registry data must be communicated to doctors, and the registry data must be given back to them so that they can see their utility. It was also noted that as cancer care moves increasingly from the inpatient to the outpatient setting, the job of the registrar will become more difficult. Dr. Flood indicated that automation of hospital discharge data, outpatient data from managed care facilities, and pathology logs will all help in collecting these data.
- Although results of a prospective randomized clinical trial comparing mammography and clinical breast exams in one arm with only clinical breast exams in the other arm showed no difference in breast cancer mortality, the panelists believe that one such study is not sufficient to change current screening practices. In addition, they noted that the clinical breast exam provides an opportunity to teach women about breast health and to check their self-examination technique. Such education and service is uneven across the Nation. Though not 100 percent effective, repeated mammography remains the gold standard for early detection of breast cancer.
- The issue of reimbursement for dental care and dental prescriptions pursuant to the treatment of oral cancers is complex; the Panel will take this issue back to policymakers for further consideration.
- A large gap and considerable tension exist between public health and the clinical arena. Someone needs to be held accountable for the prevention side of medicine; this has been lacking to date. No one has been given both the responsibility and the necessary resources for primary prevention or early detection. Those in public health take on this charge, but it is not really assigned, and no accountability mechanisms are in place.
- Epidemiologic data collection is suboptimal in virtually all settings. Yet the data that are collected, if translated into public policy, could result in changes that benefit people. This does not seem to be happening, and data reports may be so complex that policymakers do not understand them or the implications of the data. Dr. Flood indicated that epidemiologists look for changes in the data, because changes indicate that something is occurring that may lend itself to remedy, or indicate the success or failure of an intervention. Ms. Visco suggested that data that contradict standard practice are often ignored.
- To better understand some of the problems of the IHS, efforts are needed to evaluate the health outcomes of IHS patients. An increasing number of Native communities throughout the country are attempting to (and some have) take over from the IHS and manage their own health care programs. However, they are not inheriting programs that provide quality care. Lack of resources is an ongoing problem for IHS, which is funded from discretionary monies; it is not an entitlement program. Thus,

its funding is based on the compassion of Congress from year to year. Moreover, IHS is unprepared to treat the chronic conditions that now make up the majority of health problems presented by patients.

- It is possible that for Native communities close to metropolitan areas, a health care model similar to that used by the Veterans Administration, in which beneficiaries have an insurance mechanism that allows them access to the existing medical infrastructure rather than being limited to IHS facilities, might be successful. But such a model is unlikely to work for isolated Native communities. In addition, for some tribes, the provision of health care services is part of treaty agreements, and many would be unwilling to relinquish this benefit, however imperfect. Lastly, little opportunity has existed for Native Americans to experience other health care models and compare which is more satisfactory.
- Federal and State policies for eligibility for assistance need to be consistent and coordinated to avoid the type of problem experienced by Ms. Danielson. For example, thousands in Arizona are being systematically phased out of the system simply because the Federal Government raised the minimum wage while Arizona has frozen the Federal poverty level for eligibility requirements at the 1992 level. Without diminishing States' rights, Federal mandates should apply where Federal funds are involved. Instead of people falling through the cracks, the cracks need to be sealed.
- Ms. Danielson indicated that she appealed three times the decision to take away her medical assistance benefits because her income exceeded the ceiling by 66 cents. The final appeals judge indicated that while her situation was regrettable, he had to draw the line somewhere. Ms. Danielson noted that if she lived with a man who was unemployed, or if she became pregnant, she would regain her health benefits immediately.
- Since her medical assistance was discontinued, Ms. Danielson has required additional surgery. Her doctors have been willing to see her on a minimal basis for free, and the surgery was performed on an outpatient basis, free of charge. However, she did have to drive home 200 miles with a feeding tube in her nose. She believes that as many providers are as disgusted as many patients are with the current health care system. The public and the medical community need to be more vocal in trying to effect change.
- States should not be allowed to divert Tobacco Settlement funds from their intended purpose.

TOWN MEETING MARCH 8, 2001

In addition to the scheduled testimony held on March 8 and 9, 2001, the President's Cancer Panel held a Town Meeting to solicit input from the public on issues of and problems in obtaining cancer information and cancer care. The public was invited to attend the Town Meeting to raise questions and share personal experiences. Dr. Harold Freeman, Chairman; Dr. Dennis Slamon; and Ms. Frances Visco represented the Panel. Dr. Maureen Wilson, the Panel's Executive Secretary and an Assistant Director of the NCI, was also in attendance. The meeting was moderated by Ms. Carla Aragón, Anchor, KOB-TV News, Albuquerque.

OPENING REMARKS—DR. FREEMAN

- Dr. Freeman described the impetus for the current meeting series and invited participants to tell their personal stories and share their opinions as to why people do not receive the most appropriate cancer care.

Key Points

CYNTHIA CLAUS, ARIZONA

- Ms. Claus advocates for the 39 Native American tribes served by the Phoenix Indian Medical Center in Phoenix, Arizona, one of the three largest medical centers within the IHS system. She perceives a significant disconnect between known preventive oncology services, care, and treatment and the services available to Native Americans. The underfunding of IHS is a significant issue being discussed in this hotel today by representatives of all tribes and the IHS Director. Presently, Native Americans' health funding is approximately \$1,500 per capita, compared with \$3,500 per capita nationally for non-Natives. In fact, health care is better funded in the Bureau of Prisons.

Prevention and education in the current IHS system may produce a situation in which people find out they have cancer but can only access a system unable to provide adequate care and treatment. While it is possible that Indians might be sent elsewhere for treatment, there is some resistance to treatment outside the IHS system. This is because Indian tribes see the Indian Health Service as the fulfillment of an obligation from the Federal Government to the Indian people that is essentially a health care plan for which they paid generations ago; this is something they will not relinquish quickly. Relationships with the IHS currently are in transition, with tribes moving to take over their own health care. Still, whether it is the underfunded IHS or a tribe-operated system, it remains an underfunded health care system. Creative approaches to working with other Federal agencies—not just the IHS—are needed to improve prevention, care, and treatment for Native Americans. Similarly, creative pilot projects are needed in rural communities, on reservations, and in the far reaches of Alaska, where there is no access to the villages other than by boat or plane.

SUSAN NAHWOOKSY, LAWTON, OKLAHOMA

- Ms. Nahwooksy, who is Comanche, works with the ACS program called Native People Caring for Each Other. She was accompanied by Nancy Travis and Ms. Travis' mother, Leatrice Cable, a stomach cancer patient. Though their culture makes it difficult to speak about their cancer experience, they felt compelled to travel to the meeting from Oklahoma. Ms. Nahwooksy has been a caregiver to several family members with cancer. The case of her cousin, Walter Bigby, illustrates a problem unique to Native Americans who must deal with the IHS. Mr. Bigby, a Comanche, lives on the Tesuque reservation in New Mexico with his young family. He developed prostate cancer but could

not be treated there because he was not a member of the tribe originally from that area. He was forced to leave his family and move in with his parents in Oklahoma for the duration of his treatment. This was humiliating for him. His story is not uncommon among Native Americans. There are wounds to be healed in Native Americans' relationships with non-Indians, but they welcome the opportunity for dialogue about cancer care and related issues.

MARY ANNE FISK, ALBUQUERQUE, NEW MEXICO

- In the past year, Ms. Fisk has had surgery for three different cancers. She lives in Albuquerque's South Broadway neighborhood, one of the lowest-income urban neighborhoods in the Nation. Her home is near a heavy metal site, an EPA Superfund cleanup site, an interstate highway, and a site at which uranium was allegedly processed in the 1950s. In addition, the three city wells providing water to her home have arsenic levels that exceed EPA standards more than threefold. She is on a commercial and military flight path and is also near Kirkland Air Force Base, Sandia National Laboratories, and Philips Laboratories. These areas store or use many radioactive and highly toxic materials and/or conduct high-frequency microwave and laser weapons research. While she cannot state with certainty that such hazards cause cancer, she believes the President's Cancer Panel should become an advocate for governmental and private sector efforts to reduce toxins in the global environment.

More emphasis on cancer prevention outreach is needed. Albuquerque is the "skin cancer capital" of the Nation, yet schoolchildren do not wear sun hats, and there is little awareness of skin cancer as a serious problem or of prevention interventions. In addition, Ms. Fisk believes the Panel should help in addressing the current staffing crisis in health provider institutions in New Mexico and elsewhere.

DELORES GREGO, ALBUQUERQUE, NEW MEXICO

- Ms. Grego cared for her mother, who died of cancer in February 2000 at age 63. She was poor and uninsured, but she could not qualify for medical assistance because her husband received \$876 monthly from Social Security. She was not eligible for Medicare because she was not yet 65. Ms. Grego quit her job with the City of Albuquerque and withdrew her retirement funds to care for her mother and buy her medication. Her mother was able to receive assistance only when she was deemed terminally ill, at which point the State supplied her with morphine. During this time, Ms. Grego became involved with People Living Through Cancer (PLTC), a support organization in New Mexico. Through the organization, she received precious but intangible commodities: caring, compassion, and understanding. But like most nonprofits, the organization could not supply money for treatment or fund transportation to Albuquerque to get treatment; Ms. Grego's mother lived in a rural community.

Following her mother's death, Ms. Grego moved to Albuquerque and continued her association with PLTC; she is now its State Outreach Director. In this capacity, she travels throughout the State. There are hundreds of stories like her mother's. For example, two of PLTC's facilitators in Tucumcari are an elderly couple. When the wife was diagnosed, they had no money. They had to sell everything they had worked for all their lives, and now, in their 70s, are starting a new mortgage on a new home. Thus, they are starting all over when they should be retiring. "So, we hold each other's hands, and we watch each other die."

Ms. Grego noted that "the commonalty among all the rural communities and my mother's case was that while there is a lot of research, and there are cures, and there are clinical trials, and there are treatments available, they are not available to the poor."

UNIDENTIFIED MALE SPEAKER

- This speaker maintained that it is not right that people who never work can get all of their health care paid for by Medicaid, but people who work all their lives but cannot afford health insurance cannot get assistance. Other speakers pointed out the confusion among many people as to the eligibility requirements for Medicare, Medicaid, and Social Security.

BRIAN WIMBISH, FARMINGTON, NEW MEXICO

- Mr. Wimbish's 4-year-old son was recently diagnosed with leukemia (AML). He is being treated at the University of New Mexico Health Center. Mr. Wimbish praised the staff for their care of his son, but appealed for more resources for the hospital, clearer information about government assistance and insurance programs, and help for people without resources who are struggling to fight cancer.

MARGY WEINBAR

- Both of Ms. Weinbar's parents have had cancer. Though she tries to live a healthy lifestyle, she is concerned about the possibility of having a genetic predisposition to cancer. She has tried to find and enroll in a prevention clinical trial for colon cancer but has been unable to locate one. She suggests that a mechanism be established to help people participate in clinical trials. In addition, she noted that she recently called her doctor's office to make an appointment concerning a minor malady. The first question she was asked was: "Do you have insurance?"—not her name or the nature of her problem. She believes that until this mindset changes in the health community, little progress will be made. She believes it is time to establish universal access to health care.

BARBARA McINENNY, M.D., ALBUQUERQUE, NEW MEXICO

- Dr. McNenny is an oncologist practicing in Albuquerque, Silver City, Clovis, and Ruidoso. She described problems in cancer care from her perspective as a physician in a rural State. Dr. McNenny and her colleagues realized that there were a lot of people with cancer who, because it was too hard to drive 5 hours to Albuquerque or 6 hours to Tucson, decided they would just die. With the help of a local chemotherapy nurse, they began to see patients in these smaller communities. However, the distances are only one problem. The reimbursement level in New Mexico is a major problem. Dr. McNenny noted that while she can donate her time, and some drug companies are willing to donate some chemotherapy drugs, this is a hit-or-miss situation. As a small businesswoman—which all physicians are forced to be these days—she cannot afford to buy people \$10,000 worth of chemotherapy to try to treat their Hodgkin's or any other treatable type of cancer. This is a major problem.

She maintained that our insurance system is broken, and generally, people can use it only once. If one has cancer and is insured, that generally means the person is employed. If a person is too sick to keep his or her job, the COBRA law enables the patient to transfer his or her insurance and pay for it personally. However, premiums tend to be \$1,000 a month or more, which may be impossible if a person is no longer working. In addition, the deductibles, copayments, and other costs related to these expensive drugs quickly add up; most people cannot sustain this kind of expense. If a person can survive 2 years, he or she might get Social Security Disability—if work requirements have been met. However, it can occur that when a person gets Social Security, which is barely enough to live on, it may be enough to exceed the income ceiling for Medicaid. So, one can either get Social Security and eat, or get no money and have enough Medicaid to be able to get the drugs needed to live. This is not a position anyone should be in.

In New Mexico, 23 percent of people are uninsured. Many of these are working poor; the biggest group in this segment of the population are men aged 15 to 34 who are working at jobs and figure: "I'm healthy. I eat right; I exercise." Then they get Hodgkin's disease or acute leukemia, and they have no insurance. People should not have to die because they chose to put their money into their mortgage instead of buying health insurance.

Reimbursements to physicians, nurses, x-ray technicians, and other medical personnel are also lower in New Mexico. Part of the problem is that Medicare reimbursement is significantly less than that in the other States—not only Medicare managed care, which is partly fixed, but Medicare Part B as well. Providers must also pay a gross receipts tax on medical goods and services, a cost that cannot be passed on to the patient. Private practice oncologists buy the drugs, give the drugs in the office, and pay gross receipts tax on this activity. That is a significant expense, and it hampers efforts to attract oncology professionals and retain them in the State. Equalizing Medicare reimbursement across all of the States is necessary to help resolve these financial issues.

Dr. McNenny and colleagues are investing their own capital and have secured loans to build a Cancer Center in New Mexico that can provide care as it should be provided. The Center will offer radiation oncology, medical oncology, an educational Learning Center, social work services, and research.

CONNIE SOUZA, NEW MEXICO

- Ms. Souza is a survivor of ovarian cancer originally diagnosed in 1996. It was first believed she had a gastrointestinal problem. She had insurance through her employer and believes she had skilled physicians. However, when she was struggling to regain her strength after 6 months of chemotherapy, she was told she had used up all her sick leave and had to return to work. Eleven months later, she had a recurrence and, in 1998, was forced to retire. She has been disease-free since then. Ms. Souza recounted the case of a friend who also had ovarian cancer and could not afford to stop working so that she could recover from her treatments. Because she had a home and worked, she could not get Medicaid and was not old enough for Medicare. She subsequently died. A self-employed acquaintance of Ms. Souza had insurance coverage for diagnostic services, but not for treatment of her breast cancer. This person cannot afford the cost of treatment. Ms. Souza noted that we have the money to go to the moon; we should have the money to defeat cancer.

ERIC EHRMANN, ALBUQUERQUE, NEW MEXICO

- Mr. Ehrmann is a 5-year survivor of Duke's C3 colon cancer. He was diagnosed at age 47 in 1995 and given 3 years to give; he has outlived that prognosis. He expressed concern that men are not being more strongly encouraged to take advantage of preventive and early detection services such as colonoscopy and PSA testing. He noted that, unlike women, men typically do not discuss health problems or health issues among themselves. Mr. Ehrmann also believes the current structure of the health care system, particularly managed care, is a detriment to progress in men's health.

DAVID CAMPBELL, ALBUQUERQUE, NEW MEXICO

- Mr. Campbell is a 20-year survivor of childhood stage IV Hodgkin's disease. He described his attempt throughout his cancer experience to be a normal kid while all around him was a whirl of doctors, forms, phone calls, and difficult and embarrassing treatments. Although his parents said they had good insurance, he later learned that they had spent \$20,000 of their retirement fund on his treatment. Mr. Campbell believes that the technology now exists to cure most cancers, but that money and bureaucracy are barriers to care for all patients.

LOUELLA SANCHEZ-WILBURN, NEW MEXICO

- Ms. Sanchez-Wilburn now lives in New Mexico but was born and spent her early childhood in Ely, Nevada, approximately 100 miles downwind of the Nevada nuclear test range. She had cervical cancer at age 27; then breast cancer at age 47 and again at age 49. She has undergone bilateral mastectomy and reconstruction. Ms. Sanchez-Wilburn indicated that she only recently learned about her radiation exposure as a child. She is very concerned that there is no heightened surveillance program for people in her situation. Currently, for example, she cannot get a CAT scan unless she has symptoms. By then, she points out, it could be too late.

CAROLINA GERAMONTE, NEW MEXICO

- Ms. Geramonte had breast cancer last year; she went to the doctor herself because she felt an awareness of the tumor, though it was not palpable. She also has a nodule in her thyroid that is being investigated. She noted that if she pays her health insurance premiums and satisfies her deductible, she will spend at least \$10,800 on health insurance this year. Though she can afford this at this time, she wonders how those with less resources can manage these costs, particularly if they are unable to work because of their cancer. For everyone, she notes, there is a limit to the amount they can spend on health costs. In addition, Ms. Geramonte indicated that when she was diagnosed, she set about becoming educated about her disease and putting together her own treatment and support team. She appealed for government funding to bring proven cancer-fighting technology to more people and for a return to low-tech compassion and understanding from providers.

LARRY SALAZAR, NEW MEXICO

- Mr. Salazar's family, which lives in northern New Mexico, has lost at least 12 members to cancer. He believes cancer in the Española area is inordinately high. He provided a letter to the Panel outlining his concerns in more detail.

WILLIAM "BUDD" PHILLIPS, LAWTON, OKLAHOMA

- Mr. Phillips is a prostate cancer survivor. He described difficulties in getting cancer information in the middle of the country that are not experienced by those on the East and West Coasts. He notes that his area seldom receives national advertising or public service announcements on cancer or other health topics. Mr. Phillips believes if he had had adequate information, he would have been a better patient and better able to assist in his treatment. He now belongs to a prostate cancer support group, Men to Men, that also does cancer education in the community. He noted that he will be taking home many of the materials being distributed at today's meeting for use in educating those in his area.

LORETTA VALDEZ, TAOS, NEW MEXICO

- Six years ago, Ms. Valdez was diagnosed with bone marrow cancer; her father had died from prostate cancer. She was given a poor prognosis of 1½ to 2 years. She decided against taking the chemotherapy recommended by her physicians and instead sought out holistic healing methods such as acupuncture and reflexology. However, none of these treatments were covered by her insurance. She still keeps in contact with her doctors and gets her blood checked periodically. Her physicians are amazed at how well she has done. Ms. Valdez appealed for nontraditional therapies to be covered by insurance and for greater education of the public about the efficacy of these therapies.

**DR. MAUREEN WILSON, NATIONAL CANCER INSTITUTE, BETHESDA,
MARYLAND**

- Dr. Wilson encouraged the participants to seek cancer information from the Cancer Information Service (1-800-4-CANCER). The President's Cancer Panel can be reached directly at 301-496-1148, and via the e-mail address listed on the agenda and other meeting materials. In addition, Dr. Wilson invited participants to speak with PCP staff at the meeting, either to obtain information or to tell their personal stories.

MARCH 9, 2001

OPENING REMARKS, DAY 2—DR. HAROLD FREEMAN

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

STATE OF LOUISIANA

Presenters:

Dr. Jimmy Guidry

Ms. Donna L. Williams

Dr. Walter Rayford

Mr. Noah Lewis

Ms. Cindy Deville

Mr. Alan A. Hébert

DR. JIMMY GUIDRY

Background

Louisiana is rich in resources, supplying much of the country with essential industrial chemicals, yet it is a relatively poor State—22 percent of the population is uninsured, and 18 percent is on Medicaid.

For most health indicators, Louisiana ranks 49th or 50th. To help improve this situation, the State has established a Bureau of Minority Health Access. Its charge will be to determine how to deliver culturally competent services to the people who need them most. The success of the program will be measured against Healthy People 2010 goals. Other agencies in the State (e.g., Corrections, Education) are being involved in efforts to improve health status in the State.

Key Points

- Medicaid is a good program for those who have few resources, but it is not a great program when it comes to cancer. Screening mammography is the only preventive/early detection service offered for recipients aged 21 and older; it is available for women aged 40 to 99. This means that for all other conditions, there must be a disease diagnosis for services, including cancer treatment, to be provided. However, once a person is diagnosed, all services are covered, including transportation.
- Most of the disparities in cancer and other indicators in Louisiana are due to poverty. The State is determining how it can better serve its poor population and include more people under State Medicaid and other programs such as the Child Health Insurance Program (CHIP). A plan entitled *Fixing a Broken System: A Seven-Point Plan* is before the State legislature. This plan takes into account the need for patients to have a “medical home”—a regular place at which to receive primary care and other services, and where they know the providers and *vice versa*.
- The State has enough medical providers, but they are not located in many of the rural areas in which they are needed. The result is unmet medical need in these geographic areas. Louisiana is trying to expand the physician, nurse, and physician assistant workforce to better meet rural needs.
- A voluntary HMO in New Orleans is being piloted through the Louisiana State University (LSU) charity hospital system to try to improve care for the uninsured and those with inadequate insurance.

Accountability will be strengthened, and performance indicators, including cancer screening, will be tied to reimbursement for physicians who participate in the community plan.

- Louisiana also plans to establish a health care trust fund using Federal dollars. The interest earned on the money would be used to insure more people.
- Research and service provision are important to improving health status, but changing people's economic situation is the most powerful way to make a difference in their lives. If people get better educations and better paying jobs and can afford better health coverage, they usually will be able to care and provide for themselves more effectively. Toward this end, Louisiana guarantees a college education to any student graduating with a 2.0 average or better.
- We are all one serious illness away from financial devastation. Even good insurance leaves many costs unmet, not only for the patient, but for the family.

MS. DONNA L. WILLIAMS

Background

Several members of Ms. Williams' family, including her mother, have developed cancer. Thus, she noted, her work as Louisiana's Cancer Control Officer has more than professional importance to her.

Cancer incidence rates for males and females in Louisiana do not differ markedly from national averages, but cancer mortality is substantially and consistently higher. This is particularly true for the African-American population. Analysis of State data on stage at diagnosis compared with SEER averages indicates that late-stage diagnoses (and insufficient early detection efforts, particularly mammography utilization) are a major factor in the higher cancer mortality rates experienced in Louisiana.

Louisiana has the oldest continuously operating public hospital system in the country, established in 1736. The system operates on a sliding scale, and no one is turned away. In 1999, the system had 1.6 million outpatient encounters and served approximately a million under- and uninsured patients (25 percent of the State population). Over the past 3 years, the system has been shifting from an acute care philosophy to one focused on disease management, including cancer.

Key Points

- Louisiana's public hospital system is challenged by infrastructure issues, principally in terms of equipment and personnel. Equipment needs include mammography and ultrasound equipment. Because of infrastructure limitations, it is not possible to systematically perform colorectal screening at this time.
- Similarly, capacity does not exist to meet the need for both acute and chronic disease management services. It is likely that, at least for a time, early detection will take a back seat to acute care.
- Lack of resources is a continuing problem. Louisiana is often unable to make State matches required to access Federal funds, such as those for the CDC Breast and Cervical Cancer Program. Only \$500,000 has been allocated from Tobacco Settlement funds for tobacco control in Louisiana.
- Louisiana also has significant needs for professional development opportunities, and primary care doctors need resources that will encourage them to make early detection a priority.
- The State has a unique State hospital system and a culture that keeps families and communities close, but assistance is needed to develop an infrastructure that can provide culturally appropriate early detection services.

DR. WALTER RAYFORD

Background

Prostate cancer is the most commonly diagnosed malignancy in American men, accounting for approximately 29 percent of new cancer cases. Every 3 minutes, an American male is diagnosed with prostate cancer. Every 16 minutes, an American man dies of this potentially curable disease. Prostate cancer is the second most common cause of cancer death among American men.

For African Americans, prostate cancer statistics are even more devastating. Incidence of prostate cancer is 66 percent higher among African-American men than among Caucasian men. Many believe that African Americans have the highest incidence of prostate cancer in the world. PSA levels among African-American men, both those who have and those who do not have prostate cancer, are significantly higher than those of their Caucasian counterparts.

African Americans tend to be diagnosed at earlier ages and present with higher-grade and, some believe, more aggressive tumors at initial diagnosis. After surgical removal of the prostate, African-American men are less likely to respond well to adjuvant therapy. Some researchers and clinicians also maintain that African-American men have much larger tumors than do Caucasian men. Most distressingly, African-American men at any stage of diagnosis have a poorer prognosis compared to age-matched white men and are twice as likely to die of prostate cancer as their closest ethnic counterparts.

Key Points

- Prostate cancer screening began in the late 1980s. Prior to PSA screening, only 20 to 30 percent of cancers were detected at early stages. Since PSA screening became commonplace, 70 to 80 percent of cancers are now detected at early stages. Cancers detected through PSA elevation are much more likely to be confined to the prostate gland than cancers detected by the digital rectal examination (DRE). In 1996, the National Center for Health Statistics began to report a reduction in mortality from prostate cancer. This reduction is believed to be due to the use of PSA testing in prostate cancer screening.
- Some of the reasons proposed to account for the racial disparities in prostate cancer include: African-American men are less likely to participate in prostate cancer education and early detection measures; African-American men experience significantly higher PSA values; and African-American men present with more aggressive tumors at the time of diagnosis.
- In 1998, the LSU Health Sciences Center developed and began implementing the Louisiana Education and Early Detection (LEED) program. Major objectives of the program are to: develop concise educational messages about the disproportionate incidence and mortality of prostate cancer among African-American men; collaborate with lay and professional leadership in the community to develop educational programs on prostate cancer; develop strategies to identify barriers to the delivery of education and early detection efforts; and educate health providers and lay health care directors on the development and progression of prostate cancer. Other program objectives are to provide opportunities for men who have been diagnosed with prostate cancer—or for men at increased risk for the disease—to be able to discuss their concerns in a nonthreatening environment; collaborate with pharmaceutical companies and other industries about ways to disseminate clear messages about prostate cancer; invite national leaders to help disseminate messages about prostate cancer; and ensure the availability of followup care for men who have recently been diagnosed. The program's target populations are African-American men 40 years of age or older with a family history of prostate cancer, and men in the general population 50 years of age or older.
- Several recruitment strategies have been used to increase participation in this program. Voter registration polls were used to identify African-American men between the ages of 40 and 70. These

men then received an educational brochure inviting them to participate in a prostate cancer early detection effort. Public service announcements were aired on radio and television. Advertisements were placed in general and minority newspapers, and posters and brochures were placed throughout the Medical Center, as well as at sites throughout New Orleans.

- Prior to implementation of this program in 1998, approximately 300 men participated in screening annually, the overwhelming majority of whom were Caucasian. Since implementation of the program, however, total participation has increased approximately tenfold, and the number of African-American participants has increased from 25 to 30 percent to nearly 70 percent of the population. These participation levels parallel the racial demographics of New Orleans.
- LSU has also conducted a prospective study comparing the serum PSA values of patients presenting at its screening clinics in southern Louisiana. For age-matched controls, African Americans were not found to have significantly higher PSA values than their white counterparts.
- A study of Louisiana tumor registry data compared the treatments that African-American men versus Caucasian men received after prostate cancer diagnosis and also considered comorbidity related to the disease and its treatment. Among men with no or low morbidity and localized disease, the majority of Caucasian patients were selecting or receiving more effective treatment options (i.e., prostatectomy followed by radiation versus watchful waiting or hormone therapy). Thus, among patients with potentially curable disease, more Caucasian patients were receiving effective forms of treatment compared with their African-American counterparts; this difference was statistically significant. The same trend was observed for patients who had stage II prostate cancer, which, like stage I disease, is potentially curable with effective treatment.

Recommendations

- Physicians and other health care providers must take a stronger role in informing the community about current cancer information and research findings.
- States must create community programs similar to the LEED program and ensure that these programs form links to centers that provide comprehensive cancer care.
- Increased Federal funding should be provided to local and regional programs with a proven record of success to expand the infrastructure of these programs.

MR. NOAH LEWIS

Background

Born in Lake Charles, Mr. Lewis, 51, has been a resident of New Orleans for 30 years. Holding a degree in physics and math, he was an engineer for 24 years prior to establishing his own insurance-related business. He has two young adult children.

In 1994, Mr. Lewis, who was physically fit and virtually never sick, was ill for 3 days with what he thought was the flu. At his wife's urging, he went to the doctor. Blood tests showed abnormal liver function, and he was referred for a CAT scan. He was called back to the medical center, where he spoke with the head of urologic oncology, who bluntly told him he had kidney cancer. Less than 2 weeks later, his right kidney was removed. Fortunately, the cancer was encapsulated within the kidney, and he did not require chemotherapy. He was told he had an 80 percent chance of surviving 5 years.

His doctors instructed him to get an annual PSA test and CAT scan, which he did. Three years later, his PSA level was 3.1; his doctor was not overly concerned but ordered a biopsy. The laboratory evaluating the biopsy indicated that there was an abnormal cell, but that it could not clearly be identified as a cancer

cell. His doctor estimated that the chance the cell was cancerous was about 1 percent. A year later, Mr. Lewis' PSA was higher, and his physician advised "watchful waiting." Mr. Lewis decided to change doctors.

Not long afterward, Mr. Lewis' prostate cancer was diagnosed. In early 2001, he underwent a radical prostatectomy, performed by Dr. Rayford. He noted that Dr. Rayford and his team provided him with all the information he needed to make an informed treatment choice. He believes that had he accepted "watchful waiting," his disease might not have been detected in time to be curable. He expressed concern about people who have less access to information, and who are unaware of what may be going on in their bodies. Moreover, he believes some physicians apply a set of monitoring and treatment parameters to all patients that may not be appropriate for all.

Key Points

- As someone in the insurance business, Mr. Lewis was acutely aware of the potential ramifications of checking "Yes" to the question commonly included on insurance application forms: "Have you had cancer, heart disease, high blood pressure, or diabetes in the last 5 years?"

MS. CINDY DEVILLE

Background

Ms. Deville lives in Jackson, Louisiana. A 1999 graduate of LSU, she had for a year been troubled by headaches and double vision but was uninsured. Her primary care doctor put off referring her for any tests to determine the cause of the symptoms. Some time later, Ms. Deville had a traffic accident due to her double vision and decided to seek care elsewhere.

Following an appointment with an eye doctor, she was informed that she had a mass behind her left eye and should see a neurologist. Being uninsured, however, she went to the LSU infirmary, where she was referred to the Earl K. Long Medical Center. By this time, the tumor had displaced her left eye by 14 millimeters. She had surgery, which was not successful; the surgeon (whom Ms. Deville never met) could not locate the tumor, which was determined to be in the orbit of the eye. When she returned a week later for a postoperative check, the physician who had been treating her was gone. The new doctor was unfamiliar with her case and left the room to find someone who was. It was only by overhearing the conversation of these two doctors outside the room that Ms. Deville learned that she had cancer, a meningeal pericytoma. This is a very rare cancer that usually occurs in the brain, bone, or abdomen.

Her physicians found a facility that would perform an MRI at no charge. To receive further treatment, however, she would have to travel to Houma, a 3½-hour drive from her home. She was fortunate at that point to be in the care of an excellent ophthalmic surgeon. Ms. Deville had two surgeries and 6 weeks of radiation therapy. A year later, she remains disease-free.

MR. ALAN A. HÉBERT

Background

Mr. Hébert, a prostate and colon cancer survivor, was in an auto accident in 1993, and over the next 2 years required several surgeries due to the injuries he had sustained. Prior to the last of these, his blood test showed an elevated PSA. Subsequent tests confirmed that he had prostate cancer.

Mr. Hébert's family urged him to have surgery, but, in part because of the surgeries he had recently undergone, he was hesitant. His doctor explained the three principal treatment options (watchful waiting,

hormone therapy, and surgery). Mr. Hébert asked for the names of several other patients and called them, but each had a different story to tell, leaving Mr. Hébert confused as to how he should proceed. Finally, he decided to have surgery.

About 6 months later, Mr. Hébert was diagnosed with colon cancer. Six weeks after he completed his colon cancer treatment, his wife was also diagnosed with colon cancer. A year after that, she developed ovarian cancer. Mr. Hébert and his wife had Medicare and a Medicare supplemental insurance policy. Still, the copayments on their medications were so high that they were forced to use all of their savings, refinance their home (which was paid for), and sell one of their cars. They tried to obtain assistance under Medicaid but were determined to have too much income. Mr. Hébert is currently trying to obtain some financial assistance from the Veterans Administration and the American Legion, of which he is a member.

Key Points

- Medicaid helps many good people who need help, but it also denies help to people who genuinely need assistance and sometimes gives help to those who don't really need it.

Recommendations

- The Government is spending citizens' tax dollars all over the world. More should be spent to help people in this country.
- People should call their elected representatives until they get the help they need. If the representatives are not responsive to their constituencies, they should be replaced.

STATE OF LOUISIANA—DISCUSSION

Key Points

- Dr. Guidry acknowledged that even with the charity hospital system, many people in Louisiana are not getting the care they need. He believes the plan being proposed to the legislature this spring will make significant improvements in the care available to people in Louisiana, particularly those in rural areas.
- Much of Louisiana's Tobacco Settlement funds have gone to fund the guaranteed college education program, now about 2 years old. However, 42 percent of the students entering that program have dropped out. The principal reason is that many students with a 2.0 average from a New Orleans public school cannot read well.
- Ms. Deville's treatment was paid for under the State charity hospital system; she has not incurred any medical debt. Ms. Deville indicated that she believed she would have been referred for diagnostic testing sooner if she had been insured.
- The Louisiana charity hospital system is struggling to shift from an acute care to a chronic disease management focus. For example, it is aware that early detection of cancer is less costly than treating advanced disease. However, with scarce resources, the system has been unable to invest in the equipment (e.g., mammography machines) that would make it possible to provide more early detection services. The needs of acute care patients who come through the doors must be met first. As a result, for example, the hospital in Lafayette has an 18-month waiting list for a screening mammogram. Part of the LSU/Department of Health and Hospitals plan is to expand screening services to rural areas so that services can be provided in a more timely manner than is possible at overwhelmed tertiary centers. A major impediment to this objective, however, is the low reimbursements in rural areas that discourage primary care providers from practicing in those areas. A

number of closed Public Health units have been reopened with a primary and preventive care focus; these units have proven less costly to operate than previously. Local governments matched some of the State funds provided to support these facilities.

- Dr. Rayford indicated that a shift to earlier-stage diagnosis and less aggressive tumors (as measured by Gleason scores) has been observed among men participating in the prostate cancer screening program. Concerning the data suggesting that white patients are being offered more effective treatments, Dr. Rayford indicated that the data have not yet been analyzed to try to determine if black patients are more or less *accepting* of various treatment options compared with white patients.
- While anyone is eligible to receive treatment in the charity hospital system, it has some drawbacks: There is considerable paperwork to be completed; patients experience long waiting times to be seen; and because it is a teaching system, patients may not see the same physician at each visit.
- Mr. Lewis indicated that his first physician did not provide him with information about treatment options, nor did he indicate that nerve-sparing surgery was possible. Fortunately, Mr. Lewis had obtained information about this option through Internet research. He also believes that he was not told his Gleason score (it was a 6 on a scale of 2 to 10) by his white physician because the physician assumed he would not understand it. Mr. Lewis indicated that he feels strongly that people who have been through cancer have an obligation to reach out to their communities to help convey accurate information about cancer and its treatment. He noted that in New Orleans, the population is primarily black and poor. Annual income for a family of four averages \$17,000. This population has little or no health-related knowledge.
- Mr. Hébert indicated that he takes seven medications. When he could no longer pay for them, he asked his physicians for help. Some have been giving him samples provided by the sales staff of pharmaceutical companies. He is not sure how long he will be able to receive the samples.

Recommendations

- Politicians must find a way for all people to get financial help when they cannot afford needed medical care and medications. When a person is diagnosed with cancer, he or she should be given a form by the doctor that verifies the diagnosis and enables the patient to receive government assistance with treatment costs. People who can afford to pay for care should do so, but those who need help should be able to get it.

ANNOUNCEMENT—DR. FREEMAN

Prior to beginning the testimony of the delegation from Oklahoma, Dr. Freeman acknowledged his appreciation for the attendance of a volunteer delegation of Native American tribal elders who traveled to the meeting from Oklahoma to show their support. The delegation included Leatrice Cable, Clyde Nahwooksy, Clydia Nahwooksy, Geneva Navarro, and Nancy Travis.

STATE OF OKLAHOMA

Presenters

Ms. Adeline Yerkes

Dr. James W. Hampton

Ms. Eleanor McDaniel

Mr. William “Budd” Phillips

Mr. Nathaniel Walker

MS. ADELINE YERKES

Background

Oklahoma’s population numbers approximately 3.3 million people. Ten percent are Native American; 8 percent are African-American; 4 percent are Hispanic; 2 percent are Asian; and the remainder are Caucasian or other. Seventy percent of the population lives in three metropolitan areas: Oklahoma City, Tulsa, and Lawton. The remainder of the State is quite rural. Eighty percent of the State’s health care resources are in Oklahoma City and in Tulsa.

Oklahoma is home to 42 Native American tribes, of which 39 are federally recognized. Oklahoma is a nonreservation State, unlike New Mexico, Colorado, Utah, and others.

Key Points

- Before 1990, Oklahoma’s age-adjusted death rates for all types of deaths were better than the national average. From 1990 forward, Oklahoma’s death rate has increased dramatically while the rest of the Nation’s has declined. Oklahoma cancer deaths account for 25 percent of total deaths in the State. Cancer is the second leading cause of death, but cardiovascular disease and stroke deaths together represent more than 50 percent of deaths in Oklahoma. Oklahoma cancer death rates are currently below or at the national average—except for lung and cervical cancer death rates, which are higher, and about 10th highest in the Nation for both diseases.
- Premature death is considered to be death before the age of 70, the age below which the majority of the population is still very productive—either working or being caregivers and providing for the State of Oklahoma in resources and services.
- Laryngeal, tracheal, lung, and bronchial cancers account for 5.8 percent of all premature deaths in Oklahoma. They represent 6.6 percent of total deaths and 14.4 percent of reported cancers. Breast cancer accounts for 1.8 percent of premature deaths, 1.5 percent of total deaths, and 14 percent of all reported cancers. Colon and rectal cancer deaths account for 1.6 percent of premature deaths, 2.1 percent of all deaths, and 9.5 percent of all reported cancers. Brain and spinal cord cancers account for less than 1 percent of cancer deaths, less than 1 percent of total deaths, and 1.2 percent of all reported cancers.
- Since Oklahoma’s cancer registry is fairly new, data are available only for 1997. In that year, 12,992 cases were reported; of these, half were lung, breast, prostate, or colorectal cancers. Tribal nations and Federal institutions in Oklahoma, as in the rest of the United States, are not required by law to report to the cancer registry. As a result, these data understate the true cancer burden in the State.
- Under a cooperative agreement, one of the tribal nations is now reporting to the registry, and Oklahoma is in the process of devising agreements with several other large tribes. Many tribes in Oklahoma have independent health care management and ownership, including hospital ownership. The State believes these cooperative agreements to collect and share data will be mutually beneficial,

and the tribes are interested in participating. In addition, one of the larger tribes now has its own cancer registry.

- The age-adjusted lung cancer incidence rate for males is 66.9 per 100,000 and 37 per 100,000 for females. Forty-two percent of lung cancer cases are diagnosed in the later stages of the disease. African Americans and Native Americans are considerably more likely to be diagnosed at a late stage.
- The age-adjusted colorectal cancer incidence rate for males is 42.7 per 100,000; the age-adjusted rate for females is 38.4 per 100,000. Close to half of colorectal cancers are diagnosed at stages II and III. African Americans are considerably more likely to be diagnosed at a later stage.
- The age-adjusted female breast cancer incidence rate is 103.9 per 100,000. Slightly more than half of breast cancers are diagnosed at stage I; however, due to differential screening rates, African-American and Native American women are more likely to be diagnosed at later stages.
- The age-adjusted male prostate cancer incidence rate is 120 per 100,000. Staging data are not available, because most of the reporting for this disease comes from laboratories.
- In Oklahoma, approximately 20 percent of the population is uninsured. Oklahoma, Louisiana, Texas, and Arkansas all have very high rates of uninsured. Although prostate cancer is found primarily in older men, 20 percent of all prostate cancer cases are in men who are uninsured. More than a quarter of colorectal cancers are diagnosed in people who are uninsured. Thirty percent of breast cancers are in uninsured women, and 32 percent of lung cancer patients are uninsured. The uninsured in Oklahoma represent not only minority populations, but rural agricultural workers, people who work part-time, and people who work for small businesses offering no insurance benefits.
- Early detection service utilization has been analyzed for colorectal cancer and breast cancer. For years, the State ran major campaigns on breast cancer screening, and in 1990, about 50 percent of Oklahoma women had had a mammogram. Rates for minorities, however, were much lower (about 30 percent) and reflected the same proportion as women over age 65; women in this age group rarely utilized mammography facilities. Today, almost 82 percent of Oklahoma women have had a mammogram. Racial differences have all but been erased, although screening rates remain lower among Native Americans and Hispanics. In addition, all of the minorities have lower rates of repeat mammograms than Caucasians, although little racial and ethnic difference exists for the population over 65.
- Although colorectal cancer screening rates have improved over a 5-year period, little has been done in this area. Based on the partnership experience in breast screening, the State has formed an alliance with the Oklahoma State Medical Association and developed a campaign called Oklahomans for Healthy Lifestyles. The alliance has as its objective improving colorectal cancer screening by using and building on the models developed for breast cancer screening.
- Early detection of breast cancer reduces mortality in women 50 years of age and older by 30 percent. It also reduces mortality in women from 40 to 49 by 14 percent, and this is reflected in Oklahoma's mortality rates, which have remained fairly constant even though the population is aging. Like other States, Oklahoma has a Breast and Cervical Cancer Program at the State Health Department, and one Oklahoma tribe also has a program.
- Perceived disconnects that are barriers to better cancer care in Oklahoma include: lack of access for rural populations due to lower economic status and lack of health care providers; lack of research studies that translate the results of the research into benefits to research participants (particularly true of and a source of frustration for African Americans and Native Americans); the two-tiered health system in the State, comprising the university hospital, which is funded to treat the indigent, and the private system, for those with insurance; and the orientation of the payment and provider system toward acute rather than chronic disease care and management.

- Oklahoma is in the process of trying to develop a legislative task force to address affordable, accessible care and to provide a comprehensive health system for the uninsured.

DR. JAMES W. HAMPTON

Background

Oklahoma, with nearly 40 federally recognized tribal governments, is home to more American Indians than any other State. Of these, the tribes known historically as the “Five Civilized Tribes of Oklahoma”—Cherokee, Chickasaw, Choctaw, Muskogee and Seminole—account for approximately 75 percent of the estimated total tribal population of Oklahoma.

Key Points

- An Institute of Medicine report that addressed cancer in *all* American Indians cites four consistent statistics: (1) cancer is the second leading cause of death, (2) American Indians have the lowest 5-year survival rate for all cancers compared to other populations, (3) American Indians have the highest percentage of disseminated and ill-defined cancers, and (4) very little is known about prevention and treatment patterns for cancer in American Indians.
- Data on Oklahoma Indians are lacking. Appropriate intervention efforts for cancer control rely heavily upon accurate surveillance data. For a number of reasons, however, cancer surveillance among American Indians in Oklahoma is less than optimal. Perhaps the most evident challenge to collecting accurate cancer surveillance data is racial misclassification. The rate of racial misclassification of American Indians in Oklahoma is as high as 50 percent. Racial classification errors can be attributed to several factors. One of these is death certificate misclassifications. One can “be born Indian and die white.” The race *American Indian* is not included as a response category on medical intake records. In one instance, a full-blooded Choctaw woman going through the health care system was never asked if she was American Indian. Therefore, she was counted as white, and all her statistics reflect a racial misclassification.
- Evolving self-identification is another important issue. Misclassification also occurs on birth certificates. Definitions of American Indians as a race are imprecise and conflicting. Racial identity is not established at the time of health care delivery, and Spanish surnames are often used to identify race. This last issue is not particularly a problem in Oklahoma, but it certainly is in the West and Southwest, where many American Indians have Spanish surnames.
- To help improve the accuracy of cancer surveillance data in regions such as Oklahoma with suspected high rates of racial misclassification, efforts have been made in other States to link State-operated cancer registries with data from IHS and tribal rolls. This effort met with some success in Washington State, where the rate and conditions of racial misclassification were comparable to those in Oklahoma. Although Washington and Oklahoma share commonalties in terms of racial underestimation, the movement of Oklahoma tribes toward self-governance through Public Law 93-638 makes reliance upon tribal enrollment information imperative. Indeed, nearly half of Oklahoma’s tribes are self-governing, and these tribes provide health care in 5 hospitals and about 20 outpatient clinics throughout eastern and southern Oklahoma.
- If American Indians are to hope for improved cancer control and healthier outcomes, then accurate surveillance data are absolutely essential. Poor cancer surveillance of such populations exists throughout the United States, except where SEER registries exist. The issues cited above have been documented in the literature. [Dr. Hampton provided copies of a paper published with Drs. Linda Burhansstipanov and Charles Wiggins that appeared in the *Journal of Registry Management*].

- Dr. Hampton and colleagues approached the Cherokee Nation, which has a tumor registry, to enlist its support. They were invited to confer with the other four Eastern tribes and met with their tribal medical directors and tribal leaders at their Intertribal Council, which was established in 1950. The tribal leaders immediately recognized the problem and saw the need for a solution. Some reported having relatives who had experienced cancer and had been treated in Tulsa or Oklahoma City hospitals, where they had not been identified as being American Indian. They felt that finding a solution to the cancer surveillance problem was something they could support. A resolution was adopted by the Intertribal Council to endorse and support the establishment of a cancer registry for Indian people living within the boundaries of these tribes. The problem to date has been finding the funding to establish an intertribal tumor registry. The tribes hope that the Panel may be of help in finding funds to support this activity.
- Dr. Hampton recounted the stories of three American Indians whose situations illustrate the late diagnosis, advanced disease, and lower survival rates common among Indians with cancer. These cases were: (1) an Arapaho woman who 3 years ago developed signs and symptoms of colorectal cancer. She went to a federally supported facility and underwent surgical resection of the tumor. At the time of the surgery, she was found to have six positive lymph nodes. Her condition would be considered stage III. Her care ended at that point. She was never referred for any further treatment. Two years later, she had widespread metastatic disease and died approximately 3 months thereafter; (2) a Chickasaw man with metastatic kidney cancer had no access to the health care system. By the time his disease was diagnosed, the cancer had spread to the lung, bones, and brain. He survived less than 3 months; (3) a 45-year old Cheyenne woman who found a lump in her breast had a better outcome. She could not gain access to the IHS health care system to receive a mammogram and had missed the mobile mammogram unit from the Indian Health Service. She was afraid and put off seeking care until her husband insisted that she do so. She was found to have advanced breast cancer. She has now been treated and appears to be in complete remission.

MS. ELEANOR McDANIEL

Background

Ms. McDaniel, a full-blooded member of the Comanche tribe of Oklahoma, is a 3-year survivor of breast cancer.

There are presently 10,000 Comanche; they are considered one of the largest tribes in Oklahoma. Ms. McDaniel's father is one of the last fluent speakers of the Comanche language. As a child, her mother attended the Fort Sill Indian School in Lawton, where students were punished for speaking their native language. They were told it was "devil talk." As a result, Ms. McDaniel grew up in a home where she never heard the Comanche language, although her family has a long history as leaders of the Comanche Nation. Ms. McDaniel noted that while she is a full-blood Comanche, her son and daughter are only half Comanche, and her three grandchildren are a quarter Comanche. When her great-grandchildren are born, they will not meet the tribal membership requirements. In just another generation, old Comanche families such as hers will be Comanche no longer.

Ms. McDaniel and her husband served active duty in the United States Army (10 and 13 years, respectively), including service in the Gulf War. During Desert Storm, Ms. McDaniel was assigned to recover Iraqi munitions and destroy them. Using only her entrenching tool, and without any protective gear, she dug Iraqi munitions out of ammunition dumps, including live mortar rounds, small rockets, and other materiel. On returning to the United States after the War, Ms. McDaniel began having health problems, including skin rashes, breathing problems, a thyroid condition, nightmares, panic attacks, flashbacks, cramps so severe she could not walk, memory problems, depression, and breast cancer. She filed a claim for services-connected disability in 1993 and was repeatedly denied. Her physician at the Lawton Indian Hospital, who treated many soldiers coming back from the Gulf War, indicated that she

had a classic case of Gulf War Illness. Ms. McDaniel is still seeking relief from the VA. She also filed for Social Security Disability but was denied.

Although chemotherapy saved her life, Ms. McDaniel has suffered many side effects of the treatment and cannot afford the medications and medical equipment (e.g., nebulizer, eyeglasses, breast prosthesis) she needs to cope with these health problems. She finally purchased a nebulizer at a garage sale. She has been unable to get assistance or referrals from the VA, the IHS, or the Social Services department at the Indian Hospital at Lawton.

Ms. McDaniel's husband and son have cared for her through all her health problems, but the family was forced to file for bankruptcy. The family survived both the financial and health crises, and Ms. McDaniel is now trying to help others avoid the despair and hopelessness she felt during her experience with cancer.

Key Points

- Susan Nahwooksy, of the American Cancer Society in Lawton, has been instrumental in improving cancer awareness and communication among Native people through the program Native People Caring for Each Other. The program has organized a powwow honoring cancer survivors, held a traditional food dinner in conjunction with Cancer Information Day, held a Service of Hope to provide for the community's spiritual needs, and had an advocacy meeting to talk about addressing the barriers to quality cancer care.
- Programs are now being developed specifically for Native Americans, and they provide hope where there once was none. For example, Native American cancer support groups now meet on a regular basis, and other support groups are beginning to emerge throughout Indian country. With proper funding, these programs can be a means to quality cancer care for Native Americans.
- Most Native Americans live in poverty and face a host of social problems. Health care issues are numerous, and many diseases, including cancer, are on the rise. Most live in rural areas and are isolated. Most Indians do not have telephones in their homes. Isolation due to lack of transportation keeps Indians from getting to work, going to school, or getting to the hospital, even in emergencies.
- For most rural Indians in Oklahoma, no public transportation is available, and transportation plays a major role in their lives. The nearest Indian hospital is 20 miles away from Ms. McDaniel's home, and the Anadarko Indian Hospital is 60 miles away. Many patients are referred for treatment to Oklahoma City, which is 100 miles away. Ms. McDaniel noted that she has sometimes missed appointments because she lacked the transportation to get there. Her extended family comprises seven households, including her home, her two brothers' homes, her sister, her niece, her daughter, and her father. This extended family shares three vehicles, but not all are running on any given day. Recently, Ms. McDaniel's car was the only one operable, yet a car is virtually the only means of transportation available.
- Unemployment in the State of Oklahoma is a disease. State license tags proclaim that Oklahoma is Native America, but many employers do not hire Indians because they are labeled "unreliable."
- Quality medical care is beyond the reach of most Indians because many are unemployed and cannot afford health insurance. There are two major hospitals, Memorial and Southwestern, in Lawton, but their services are not afforded to many Native Americans. Health care for Native Americans is seriously misunderstood; many believe that because of IHS, Native Americans get the best quality care anytime, anywhere, and without cost. In truth, many "fall through the cracks," since they cannot get adequate care at the IHS facilities, do not qualify for any of the public health programs, do not have Medicare, and cannot afford private health insurance.
- The Lawton Indian Hospital is funded by the Government through the IHS and provides services to approximately 50,000 Indians in the community. However, any card-holding tribal member of any of

the approximately 650 federally recognized tribes in the United States has the right to obtain services at this facility, which was originally established for seven local tribes. Now even non-Indians who qualify for public health care are eligible for services at this small hospital. At one time, the Lawton Indian Hospital was a hospital in the true sense of the word, but today it exists only as a clinic that handles general health care. Though the facility has come to serve far more people, its funding has stayed the same, and it cannot meet the needs of the people. It operates using outdated equipment and lacks medicine, supplies, and staff. The medical staff are all young, inexperienced interns from foreign countries. As inadequate as it is, the Lawton Indian Hospital is the only source of care for many Indian people in Oklahoma.

- Testing, treatment, and other care provided outside the IHS facility must be approved by a contracted outside organization, Contract Health. This is done on a case-by-case basis. Ms. McDaniel, for example, was referred out for MRIs, screening, testing, mammograms, and chemotherapy. Contract Health meets weekly to determine what referrals will be approved. Currently, Contract Health is spending \$23,000 every 3 months for a patient receiving treatment for lung cancer. At that rate, Contract Health's \$2.75 million budget will quickly be expended.
- The Native American population used to be numerous, but it now makes up not quite 2 percent of the national populace. For their vast lands and resources, they were given only promises, one of which was health care. Is it too much to ask the Government to make good a promise to a population so few in number that it verges on extinction?

MR. WILLIAM "BUDD" PHILLIPS

Background

Mr. Phillips is a prostate cancer survivor, retired from the military, and a 100 percent disabled veteran. He has become a volunteer veterans' benefits advocate, assisting veterans and their wives, widows, and orphans who need assistance from the Veterans Administration.

Mr. Phillips is a Vietnam veteran, and the Veterans Administration has determined that prostate cancer is a possible side effect of exposure to Agent Orange. Because of this ruling, he has been able to get good care through the VA that he would not have been able to afford on his own.

Key Points

- Mr. Phillips experienced significant difficulty in finding information related to his disease so that he could make informed decisions about his care. He did not get this information until he entered the VA system and was provided information by his urologist. He indicated that such information is not generally available to the public in Oklahoma.
- In southwest Oklahoma, there are only three locally owned television stations available if a person does not purchase cable access. These three stations do not air any public awareness programming or announcements on cancer; instead, they air paid advertising.
- Southwest Oklahoma lacks public transportation, which limits access to information and care. As a volunteer, Mr. Phillips transports VA patients to Oklahoma City in his personal vehicle two or three times per week. The round trip is 200 miles.
- The Disabled American Veterans has a van that can transport ten people. It goes from Lawton, Oklahoma, to Oklahoma City daily, leaving at 5:15 a.m. and returning at 3:30 p.m. If a patient's appointments do not fall within that timeframe, other transportation arrangements must be made. If a patient's appointment causes him or her to miss the van, there is no choice but to beg a ride from someone in the hospital or be faced with staying overnight in Oklahoma City.

- The informal volunteer transportation network seems to work well for the World War II and Korean War veterans, but veterans of Vietnam and the Gulf War are resistant to accessing the VA system at all. They do not want to deal with the paperwork that is involved with the VA system, and many get jobs that offer health benefits so that they will not have to receive care through the VA.
- Many veterans, especially those who are Hispanic or Native American, resist the digital rectal exam necessary for prostate cancer screening and monitoring, particularly if the examiner is female. They believe submitting to this test is degrading. These patients also often do not want their families to know they have cancer.
- Some improvement has been achieved in communicating with people as they are leaving military service. The VA now provides information on how to file a claim. This has been a big step forward, since many veterans have avoided the system because they do not understand it or understand how to make it work for them.
- The VA facility in Oklahoma City has recently begun making arrangements and coordinating care with local providers, especially those at the Department of Defense facility at Fort Sill, to perform laboratory and x-ray services not previously available. In addition, the VA hospital in Oklahoma City has become a teaching hospital. Physicians from Baptist University and the Oklahoma University Health Sciences Center are now doing rotations in the facility, and this is improving the quality of care provided. More such arrangements and coordination with local providers are needed to bring better care to remote areas.
- Like Mr. Hébert, Mr. Phillips believes that more direct communication with elected officials is needed. He recounted how, at a community meeting, he told his own elected representative that he would be more than satisfied to have the same health care system the Congressman himself enjoyed.
- The VA now has an outpatient clinic in Lawton, but it is understaffed. Though the clinic is supposed to provide outpatient psychiatric services, the psychiatrist position has never been filled. Patients in need of these services may be referred to Oklahoma City, but it can take 5 or 6 months to get an appointment.
- Like Native Americans, veterans are dependent on Government-funded health care to survive. If the Government funds are not provided, these populations suffer.

MR. NATHANIEL WALKER

Background

Mr. Walker, 70, has lived since his retirement in 1985 on a ranch about 12 miles from Muskogee, Oklahoma. He had always been in excellent health. Mr. Walker had given up his private insurance because of the cost. He first accessed the VA system in 1995, on the advice of his private physician. At that time, he asked to have his prostate checked, which had not been done for approximately 25 years. The doctor was concerned about the result, and Mr. Walker was given an abdominal x-ray. The x-ray showed a mass in the colon, and he was referred to Oklahoma City, a 2-hour drive, for a colonoscopy and second opinion.

Mr. Walker has a close-knit family in the area; his brother drove him to Oklahoma City the next day, but he could not be seen. He returned home and drove back again the next day, when he received the colonoscopy. The test revealed so large a mass that the camera could not get by it. Four feet of his colon were removed, and although his lymph nodes were clear, he was advised to undergo a yearlong regimen of chemotherapy, which he did.

Shortly after Mr. Walker finished his treatments, his wife was diagnosed with brain cancer. At the same time, Mr. Walker's PSA level kept rising; he was diagnosed with prostate cancer and underwent nonsurgical treatment.

Because of his experiences, he urged his brothers to have colon and prostate checkups. Two of his older brothers were found to have prostate cancer. Because his father and grandfather had also had prostate cancer, Mr. Walker strongly suspects a hereditary component to the disease in his family. He strongly urged anyone who suspects he or she may have cancer to get screened.

DISCUSSION—STATE OF OKLAHOMA

Key Points

- In Oklahoma, women aged 50-64 are most likely to receive screening mammograms; followed by those aged 40-49, then women younger than 40, and least frequently, women over age 65.
- Very little money has been set aside for cancer screening in tribal health facilities, although some receive limited support from IHS. However, screening is considered a luxury, and the tribes do not have the money to pay for cancer treatment. Consequently, there are few cancer screening efforts. Cancer treatment would deplete most tribal health funds if they were asked to provide it.
- Although CDC-funded grants for screening breast and cervical cancer have been effective, funding has not expanded. Currently, only 15 of the 500 U.S. tribes have federally supported screening capability. Once breast or cervical cancer is detected, there is no further funding to provide medical care, since American Indian women are excluded from Medicaid support. Ms. Visco noted that with the recent passage of the Breast and Cervical Cancer Treatment Act, women who are diagnosed with breast or cervical cancer through the CDC Breast and Cervical Cancer Prevention Program will be automatically Medicaid-eligible for their treatment. However, each State has to opt in, and a “credible coverage” issue remains that Ms. Visco's organization is working to resolve. This credible coverage issue is the basis for the current exclusion of women covered under the IHS.
- Oklahoma has a very poor Medicaid system (ranked 45th out of 50). There really is no cancer care provided for poor, underserved American Indian women. This is discrimination against all American Indians because the Government has promised that the IHS would provide total care for Indian people, yet IHS appropriations are so low that it cannot provide comprehensive medical care to cancer patients. Legislation has been introduced to try to correct this situation and enable Native American women who meet other eligibility criteria to access Medicaid.
- To improve recruitment of minorities into clinical trials, it is necessary to establish a partnership with the target populations, including rural populations, so that they can provide information about their needs and concerns. This extends not only to clinical care, but to behavioral science that recognizes culture and differences. For example, Ms. Yerkes' office works with Native Americans in Oklahoma through the Reach 2010 project. The State receives funds from the CDC to reduce health disparities. This is the first time that Native Americans have had a say in how research will be conducted in Oklahoma. They are very proud of this effort, and it should serve as a model for the Nation.
- In Oklahoma, 42 Native American tribes are federally recognized, though there are other tribes residing in the State. The “Five Civilized Tribes” is a designation given by the young American government to the five tribes that agreed not to make war on white Americans. Though this term is commonly used, it has never been accepted by the Native American population.
- Correct racial classification of Native Americans is important because most Federal grants for cancer research and health care improvement are based upon cancer surveillance data. Lacking those basic surveillance data, Native Americans have little hope of improving the outcomes of cancer care

delivery. Surveillance data are absolutely essential to knowing treatment outcomes and survival for cancer in Oklahoma Indians, as well as to enable evaluation of the types of treatment received and whether their cancers are more aggressive or virulent than those occurring in other populations. The link between State statistics and tribal statistics that has been forged in certain States, including Washington and Idaho, has helped to improve outcomes. However, such efforts require funding, which the State Health Department does not have. Federal support for an Intertribal Tumor Registry is needed. The Cherokee Nation has a SEER grant that enables it to operate its cancer registry. Dr. Slamon suggested that given Oklahoma's unique population, SEER should be approached about infusing funds into the State for cancer surveillance. It was noted, however, that SEER data were never meant to be comprehensive; they could be, but the additional investment would require Congressional and Presidential endorsement and support.

- It was noted that in New Mexico, the Vietnam Veterans of America (VVA) set up a van service to help get veterans to the hospital and also established a bus token program to enable homeless veterans to reach the VVA. Lawton, Oklahoma, has a large VVA chapter, with 241 members. The chapter is working on getting transportation coordinated, but does not currently have enough funds for a van. A ride-sharing program has been established instead. Mr. Phillips noted that the VVA Council decided it was more important to have a State monument than a van.
- In Oklahoma, no organization exists equivalent to the New Mexico All-Indian Pueblo Council. The tribal governments are always in turmoil, with the major concern being issues related to gambling, since gaming is the tribes' major source of revenue. By contrast, cancer is a low priority. Oklahoma has only a few Native Americans in its legislature.
- Ms. McDaniel explained that when she first became ill after returning home from the Gulf War, she immediately filed a claim with the VA for service-connected disability. Knowing the system is extremely slow, she waited a year for a response. When she went back to inquire about her case, she was told that more information was needed. At that time, she was extremely ill, and her family had filed for bankruptcy. She made it clear that she had no source of care and no income and needed help. She was told she could qualify for a medical card and Social Security. When she asked why she had not been told this, the reply was: "You didn't ask." Ms. McDaniel filed a statement with the regional office on the way she had been treated. Two VA representatives came to talk with her and her husband; they offered only an apology. Her claim for benefits has been denied repeatedly. She suspects that her claim has been denied because she was a female, lower-level enlisted person with noncombat status. However, as administrative assistant and driver for a commander, she was at the front continually and lived for over 2 months in the environment of oil smoke and soot unique to the Gulf War situation. Ms. McDaniel indicated that the Indian hospital was compassionate and did what it could for her with its limited resources. She believes the only real cure for cancer and its side effects is funding.
- Mr. Phillips said that the runaround Ms. McDaniel experienced at the VA occurs commonly with both Native Americans and women. In a case such as hers, Congress has allowed the VA (through Title 38 of the United States Code) broad latitude as to how to treat (or not treat) Gulf War-related illness. He noted that many hospitals on the East and West Coasts treat Gulf War veterans promptly and thoroughly. New rules have been enacted such that veterans simply have to state that they were in the Gulf War and they are eligible for treatment. These reflect the Government's relatively recent acknowledgment that Gulf War Illness is real.
- Mr. Phillips also indicated that Gulf War participation aside, had Ms. McDaniel been properly informed, she could have completed a one-page form and been treated promptly for her breast cancer at the Oklahoma City VA hospital. He believes that, in part, she experienced the problems she did because she was dealing with people working for the Oklahoma State Department of Veterans Affairs; these people are not VA employees and sometimes are not fully informed and able to give a

veteran proper advice. He believes this situation is improving through better education of these personnel.

- The Indian Hospital at Lawton is open to any person holding a tribal card, and the facility also may be open to non-Indian Medicare and Medicaid beneficiaries. This is not the case in other States, in which IHS facilities serve only local tribes or provide care to those not members of the designated tribes only for minor conditions. Individuals who experience a major illness or injury have to return to the facility to which they were originally assigned, even if they no longer live in that area—or even in that State.
- Ms. Nahwooksy suggested that the old-line Southern thinking of the majority population in Oklahoma causes Indians to be discouraged from using their VA benefits because it is believed that Indians should receive care only through IHS. She also noted that each tribe can establish its own blood quantum requirements (i.e., the amount of Indian blood one must have to be considered a member of the tribe). For many tribes in Oklahoma, one must be at least one-quarter Indian, but other tribes have lowered blood quantum requirements to such a degree that people are “becoming Indian overnight” (are able to prove Indian lineage based on the Dawes rolls of the 1880s); many of these people are not part of an Indian community and scarcely know to what tribe they are related, but they become eligible for care at IHS facilities. This situation has contributed substantially to the increased patient volume at these facilities, which were already underfunded. There is some controversy as to whether the solution to the problem is to provide more funding or to become more exclusive. The real issue, however, is the need to provide appropriate care to all who need it.
- Another factor complicating this issue is that after the wars with the Indians, the Government settled with the tribes in different ways. For example, the Navajo settled and got one large parcel of land as a reservation. Most of the tribes in Oklahoma received allotments. As a result, more money is allocated to the reservation Indians than to the individual tribes that do not have reservations. Since there are few or no reservation Indians in Oklahoma, this population receives far less money than any of the other Indians in the United States.
- The issue of tribal membership is extremely complicated and goes back to the first contacts with white people who came to America. There are approximately 1,000 treaties and Executive Orders that tribes must deal with relative to Indian life in this country. It was also noted that although tribes may decide who is a member based on blood quantum, they are also required to have a constitution modeled on the U.S. Constitution.
- An Indian Health Board does exist, made up of the leaders of the different tribes. The budget of the IHS is determined each year based on testimony before Congress, however, and while the Indian Health Board provides information, the Indian community itself is never asked to participate.
- It was suggested that a special panel be convened to further explore these issues as a followup to the Panel’s work.
- Dr. Freeman acknowledged and accepted the invitation of the governor of the Santo Domingo Pueblo to visit the pueblo the following day.

STATE OF TEXAS

Presenters:

Dr. Nancy S. Weiss

Ms. Mickey L. Jacobs

Ms. Pat Graham-Casey

Mr. Jaime de la Isla

Ms. Debra Long

Ms. Annie Mary Johnson

DR. NANCY S. WEISS

Key Points

- A cancer registry is the ongoing systematic collection of data on the occurrences and characteristics of reportable neoplasms. A registry is needed to determine who gets cancer, the types of cancers diagnosed, the stages of disease at diagnosis, the types of care received, and populations at increased risk. Registries are also used to investigate concerns about possible excesses of cancer and to evaluate the success of interventions. These data also help in understanding the causes of cancer, which can lead to prevention interventions. The data can also lead to special research studies. Registry data are also used to plan health care delivery systems and place facilities and services where they are lacking. Lastly, cancer registries help with cancer education programs.
- A barrier to good cancer care is having either no central cancer registry or a central cancer registry that lacks complete, timely, and quality cancer information. This is the current situation in Texas. Cancer reporting in Texas is limited to hospital and cancer treatment center information. It does not include reporting from physicians, freestanding pathology laboratories, ambulatory surgery centers, or other types of outpatient cancer facilities that may diagnose or treat cancer patients. Therefore, bias in the available data is likely. For example, prostate cancer, melanoma, and cervical cancer patients may go to other medical care settings from which the registry does not receive information. Thus, the true incidence of these cancers may be underestimated.
- The Texas Cancer Registry data are not timely. The most recent data currently available are for 1997. This makes it very difficult to measure the success of cancer control interventions and subsequent outcomes in 2001. In addition, the quality of Texas cancer information is lacking. Only sporadic quality assurance activities have been possible. For example, 23 percent of the case data are unstaged; therefore, it is difficult to draw conclusions as to whether patients are being seen at earlier stages of disease.
- Establishing and maintaining quality cancer data requires both legislation and regulation: the first to require reporting from all relevant sources, and the second to stipulate the timeliness of that reporting.
- Cancer registry efforts in Texas are hampered by the State's geographic vastness, across which a population of 20 million is distributed. Funding also plays a very important role. In Texas, roughly 10 cents per capita is allotted for cancer registration. It has been estimated that a minimum of 30 to 40 cents per capita is required to have a well-functioning cancer registry.
- Caseload is another important factor, including both the number of reporters and the number of cases handled. Currently, more than 500 reporters provide data, and roughly 73,000 cancer cases were diagnosed in 1997. Adequate funding for this effort is also crucial.

- Staff qualifications are important, for the staff both in the facilities that report the data and within the central cancer registry to process and analyze the data. Texas has a lack of certified tumor registrars and of education programs that train individuals to become certified tumor registrars.
- Texas is still in the “Dark Ages” when it comes to information technology within the cancer registry; the database is still a DOS-based system. Issues in trying move forward with information technology involve both the adequacy of funding and personnel to address these issues.
- At this time, Texas is unable to meet its data users’ needs because it does not have the complete, timely, and quality data needed to address the issues of cancer care, control, and prevention. Data from a cancer registry are basically worthless if they are not put to good use.
- Cancer registry funding comes from both general revenue dollars and specified tax dollars. Currently, the Texas Cancer Registry receives general revenue dollars, but no monies from the Tobacco Settlement dollars are earmarked for cancer registry activities. It does receive Federal funding from the CDC under the National Program of Cancer Registries, but Texas is not eligible for any of the SEER registries’ funding because it does not meet the minimum requirements for timeliness, completeness, and quality.
- The overall goal of the Texas Cancer Registry is to collect complete, timely, and accurate cancer data on cases diagnosed in the State. The State recognizes the areas that are weak and is making strides in trying to improve them. One such initiative is proposed legislation to require physicians and other health care practitioners to report cancer cases seen solely in their offices. In addition, the Registry has asked for an increase of approximately \$2 million annually in State funding to help subsidize the Cancer Registry and to allow it to catch up and be more timely, handle the additional records that will be coming in, and do quality assurance studies. The Registry is also undertaking a thorough evaluation of its information management and process systems to make recommendations for enhancement.
- Complete, timely, and accurate registry data are essential for good cancer care. Without a cancer registry, we have no way to identify where we need to go, much less to evaluate where we have been.

MS. MICKEY L. JACOBS

Key Points

- Texas has a 15-year history of commitment to cancer control with a very comprehensive approach from the State legislature and the Governor. Over 15 years ago, the Texas Cancer Council, a somewhat unique model in the Nation, was created. Whereas many cancer programs are categorical, with funds aimed at a particular kind of cancer, this agency is designed to fund many different types of cancer care throughout the continuum—from prevention to screening, early detection, and all the way through to end-of-life care. Most importantly, noncategorical State dollars are attached to that commitment. Use of the State dollars devoted to cancer prevention and control is guided by the State Comprehensive Cancer Plan. The Council is responsible for creating the Plan, but it is a plan for the State and all of its public and private cancer control partners. Texas believes in leveraging resources by forming partnerships so that things that any one entity could not accomplish alone can be accomplished to a greater extent through these State and local partnerships.
- Texas has more than 20 million people residing in 254 counties that cover 260,000 square miles. Texas is second only to Alaska in terms of geographic area. This large land mass complicates attempts to provide effective cancer control.
- The minority populations served in Texas include African Americans, who bear a much greater burden of cancer morbidity and mortality; Hispanic or Latino populations; and Asian populations.

Both the Asian and Hispanic populations comprise subgroups of people with varied languages and backgrounds. Texas also has a small but important Native American population.

- Texas ranks near the bottom nationally for insurance coverage and per capita income. These problems are especially difficult to address because the population is dispersed over such a large land mass.
- The Cancer Council's efforts are aimed at providing seed money for local communities to focus on the needs of underserved populations. This is accomplished through: (1) local community initiatives; (2) statewide initiatives, particularly in the area of primary prevention; and (3) professional education. Currently, 29 initiatives are being funded. Examples include a colorectal cancer screening and awareness program in El Paso, the African American Women's Breast Cancer Outreach program, and the mobile mammography clinic that serves women in 35 rural counties.
- Despite these positive steps, the Council's \$4 million budget is grossly inadequate for the needs of the population. The cost of cancer care in Texas is estimated to be about \$13.9 billion, including direct and indirect costs. More funding is needed.
- People in Texas face the same economic, cultural, and geographic barriers faced in many other States. One thing that can be done is to communicate the importance of locally based cancer control programs and to apply what we already know. As important as cancer research is, many cancers, particularly colorectal cancer, are quite literally preventable and curable with the right screening and early detection. For many cancers, new research or new technology is not needed; we simply need to apply better what we already know.

MS. PAT GRAHAM-CASEY

Background

The Cancer Consortium of El Paso, Incorporated, a part of the West Texas Community Care Consortium, was originally funded in 1989 by NCI to develop a consortium to address disparities in cancer screening. The vision of the Consortium is to achieve a community in which residents are free of needless suffering from cancer and chronic disease and are active partners in a prevention-oriented health care system that is integrated, comprehensive, and nondiscriminatory.

The Consortium serves all of the people within a 12-county region in West Texas. These counties are connected by their demography and the challenges they face, as well as being a natural urban and rural market networked service area. These 12 counties cover 31,000 square miles and include the largest counties in the State. For example, Brewster County alone is larger than the State of Illinois. People who live in Brewster County must drive up to 240 miles for care. Residents of some of the other counties travel 90 miles to receive tertiary care in a county hospital. These counties comprise a rural corridor dotted with towns that run between the large communities of Midland and Odessa to the east and El Paso to the west. Long distances separate hospitals, health clinics, and the few health care resources in the area both from each other and from those they serve. A major portion, if not all, of the counties are considered medically underserved areas and health care professional shortage areas. The physician-population ratio is 1 physician to 844 people.

Key Points

- Barriers to cancer screening and treatment include transportation, large minority populations, language, lack of insurance, unemployment, poverty, lack of culturally competent providers (three counties have no physician at all), poor continuity of care, fear, State eligibility standards and guidelines that are too difficult to allow people to access Medicare and Medicaid, and the government in general.

- In addition to operating in a State with a high proportion of uninsured people, the region is home to very high concentrations of people of Hispanic origin. Of the 773,227 people in the area, 72 percent are Hispanic. Eleven of the 12 counties have a higher percentage than the State average of 45 percent Hispanic. This population has special issues regarding employment, language, and access to care. The people living in these communities face a daunting array of barriers to care and wellness.
- One of the community workers in West Texas and El Paso noted that even with insurance, patients typically have to wait several days for an appointment with a physician. This issue raises serious issues for the Breast and Cervical Cancer Screening Program. Women are being diagnosed and then have to wait long periods for treatment; cancer diagnosed at stage I can quickly become stage IV under such circumstances. In addition, it often takes 90 days or more to secure Medicaid approval, and this, too, can be a major impediment to prompt treatment.
- Minority populations often fear government intrusion related to cumbersome paperwork, and are frequently unaware of the resources that might be available to them.
- Available programs are often disease- and site-specific, with nothing available for the whole person. This situation makes continuity of care impossible.
- The Consortium serves a part of the country that has extraordinarily high numbers of people without insurance. Texas has the highest rate of insurance indigence in the United States. The overall rate of health insurance indigence in the U.S. is 16 percent; in Texas, by comparison, it is 27 percent. In West Texas, 31.8 percent are uninsured.
- Unemployment rates in Texas are 5.7 percent; in West Texas, unemployment is approximately 9 percent. Poverty rates in Texas are 16.5 percent; in West Texas, they are as high as 23.5 percent in the 12 counties. The 12-county region is home to 187,000 uninsured people between the ages of 19 and 64. These people are not covered by Medicaid, and will not be covered by the CHIP program.
- The West Texas minority population is 16 percent higher than the Texas average. The Hispanic population in the region is twice the statewide percentage. Ethnicity and language can be substantial barriers to health insurance, as well as to the efficiency and quality of health care. Over one-third of the people in the 12-county area require communication in Spanish.
- Age-adjusted cancer incidence and mortality rates among Hispanic males and females in West Texas are higher than the State average. Men, in particular, have higher mortality rates, in part because they do not access health care.

Recommendations

- Ms. Graham-Casey, a cancer survivor and former Medicaid recipient, believes that possible solutions to some of the issues particular to West Texas include: (1) simplifying Medicaid access; (2) eliminating the asset test required by the State of Texas (though not by the Federal Government); (3) eliminating the face-to-face interview (also not required by the Federal Government); and (4) allowing provider screenings in rural and urban areas.
- In addition, it is necessary to reduce the number of self-pay patients and the strain on the indigent pool of funding that rural counties are presently experiencing. Tobacco settlement monies should be focused on health care, as was originally intended; these funds are being used to pave roads and repair golf courses in West Texas.
- Patient access to providers must be improved. If Medicaid were easier to access, and physicians had a reasonable expectation of reimbursement for their services, they might be enticed to practice in rural communities.

MR. JAIME DE LA ISLA

Background

Mr. de la Isla is an Assistant Superintendent with the Houston Independent School District. He is also one of 80,000 to 100,000 cancer survivors in the Houston area. Four years ago, while attending a national education conference in Albuquerque, he first began to suspect that something was wrong. Upon returning home, he saw his physician, who referred him to a specialist. This specialist discovered a cyst located in the lower floor of Mr. de la Isla's mouth. Following removal of the cyst, Mr. de la Isla was diagnosed with synovial cell sarcoma. He was told that further surgery was needed to remove any remaining cancer, and he was given an MRI to determine the extent of any residual tumor in his mouth. In addition, Mr. de la Isla was told that it would probably be necessary to break his jaw and perform reconstructive surgery. He would be given a tracheotomy to allow him to breathe during the expected swelling. He was also told that there was a strong possibility that part of his tongue would have to be removed. He would be hospitalized for 7 to 10 days, with a month of recuperation at home. Six weeks of radiation therapy would be necessary after the surgery. Mr. de la Isla was told that the survival rate for his type of cancer was about 50 percent at 5 years.

This news left Mr. de la Isla in complete shock. His mind filled with fear and questions: How would he tell his children, family, friends, and colleagues that he had cancer? How would cancer affect his future as a public school administrator? Would he be disfigured by the surgery? How well would he be able to speak? Would others be able to understand him? And, as a single parent living alone, who would care for him and his daughter while he recuperated at home? How long would he have to live?

Mr. de la Isla survived his 10-hour surgery and the subsequent radiation therapy and recuperation and is fully recovered. In addition to his full professional and social life, he has become an active volunteer with CanCare of Houston, a cancer support network. In that capacity, he encourages others, stressing that there is life after cancer and that effective communication and positive relationships with the medical team are paramount for recovery.

Key Points

- Latinos in the United States face greater health risks than does the general population due to issues related to access and ability to navigate the health care system. Latinos are more likely to be unemployed than non-Hispanics. Latino children are more likely to be living in poverty than non-Hispanic white children. Poverty, lack of insurance, limited education, limited access to health care, lack of awareness of breast cancer in Hispanic women and of prostate cancer in Hispanic men, inadequate physician referrals, acculturation levels and barriers related to language and culture, and negative provider attitudes play important roles in the lower rates of screening and preventive services among the Latino population.
- Moreover, although Latinos currently make up 11.7 percent of the population in the United States, they account for 25 percent of uninsured Americans. Consequently, Latinos who do not have access to health coverage are less likely to receive preventive services, have a regular source of care, and receive medical treatment. They are also more likely to delay seeking care, use the emergency room as a regular source of care, and face poor medical outcomes and premature death. Uninsured Latinas with breast cancer are more than twice as likely to be diagnosed at a later stage than non-Latinas. Uninsured Latinos with prostate cancer are almost four times more likely to be diagnosed at a later stage than non-Latinos.

Recommendations

- There are very limited data on cancer among Hispanics in the United States, and more research on Latinos and disparities in cancer care among specific Hispanic groups—whether Mexican-American, Puerto Rican, Cuban, or Central/South American—is vital. But equally as vital is making relevant distinctions between, for example, rural and urban, and between immigrant and first-, second-, and third-generation Hispanics.
- The President, together with Congress, must provide greater legislation and funding opportunities to create a nationwide campaign for access to information and cancer care among Latinos, minorities, and other medically disadvantaged groups. Such a major public relations campaign targeting the Nation’s Hispanic community and utilizing the Spanish language must be developed and administered effectively.
- The medical profession must be properly trained to build greater trust and confidence with the diverse cancer patient community. Health professionals must possess not only the medical and technical skills to heal, but also a greater sensitivity to care for this distinct population group. Medical schools and health-related graduate programs must provide opportunities to identify, recruit, and retain Hispanics in the health professions, with incentives to serve the Spanish-speaking cancer community.
- Local support organizations should have greater financial opportunities to serve cancer patients and their families.

MRS. DEBRA LONG
MR. ROBERT LONG

Background

Mrs. Long, who has five children, is from Perryton, Texas. Her husband works full-time, but his employer does not offer medical insurance. When she was diagnosed with head and neck cancer, Mrs. Long was sent to Amarillo for treatment but was told that the facility did not do the type of surgery required. Mrs. Long subsequently found out that this was not the case and believes she was turned away because she was uninsured. The facility in Amarillo referred her to a hospital in Dallas, where biopsies were performed. However, the Dallas facility declined to perform any further tests or admit her to the hospital, although Mrs. Long indicated that she had applied for Medicaid. She was sent back to the Amarillo facility, where she was again denied treatment.

At this time, Mrs. Long’s husband had arranged an appointment for her to be seen at a hospital in Galveston. She was told that she could be treated there despite her lack of insurance. However, Galveston is an 18-hour drive from Mrs. Long’s home, and she was concerned about being so far from her family. The hospital in Galveston indicated that the same surgery could be done in Lubbock, which was closer to home. However, the facility in Lubbock would treat her only if she paid \$15,000 up front. She returned to Galveston, where the surgery was performed. Mrs. Long was in the hospital for about a week. Before she was discharged, however, all her teeth were pulled because they were in poor condition and would be unable to withstand the radiation therapy she required. She was sent to a local motel but was not given antibiotics. She developed several fistulas that necessitated reconstructive surgery and a “full-flap” incision extending from ear to ear. One day after she was discharged, Mrs. Long and her husband were forced to give up their motel room because it had previously been booked as part of a fraternity weekend in the city. They had to go as far as Houston to find another hotel.

Because of all the complications Mrs. Long experienced, her anticipated 1-week stay in Galveston stretched to 4 months. Because of her stapled incision, she could not travel the 1,000 miles home to see her family.

Mr. Long maintained that they were treated so poorly from the outset because they lack insurance. Because he worked, they were not eligible for any medical assistance and were dependent on family, friends, and the churches in their hometown for help. In caring for his wife, however, Mr. Long was unable to work for 4 months, which enabled them to qualify for the “spend-down” for Medicaid.

It has been nearly a year since Mrs. Long’s diagnosis, and she still is struggling with the effects of her disease and its treatment. She has been slow to heal because she is also diabetic and for the past few months has struggled with pneumonia. Because there are no health facilities in her area, Mrs. Long still travels 1,000 miles every other month to visit her doctor.

Mr. and Mrs. Long expressed their wish that improvements be made in the health care system so that no one has to go through experiences such as theirs.

MS. ANNIE MARY JOHNSON

Background

Ms. Johnson is a 16-year survivor of metastatic breast cancer. She had worked for an oil-related company doing seismic data processing; she made a good living and had excellent insurance. When the Texas oil boom collapsed in the late 1970s and early 1980s, however, she was left without a job or insurance. In February 1985, she discovered a nodule in her breast about the size of a black-eyed pea. Her doctor told her not to worry about it because black women have fibrocystic breasts. However, Ms. Johnson remained concerned; she had many family members in the medical field and had herself worked in and around hospitals for many years. In addition, she had a strong family history of cancer. She went to two other doctors and received the same advice.

In June 1985, she went to yet another doctor (the fifth since discovering the nodule), who asked if she had ever had a mammogram. None of the previous physicians had suggested she do this. Though she could get an appointment for the following day, the cost would be \$295, which she did not have. The doctor insisted she have the test and made telephone calls on her behalf until he found a facility that would perform the test that day for \$65. She was called back to the doctor’s office the next day, where she was told she had breast cancer. When she told the doctor that she had no insurance, he offered to do the surgery for \$4,000 and indicated that the hospital charges would total approximately \$6,000. Ms. Johnson said she would have to try to sell her home. The doctor told her to come back when she got the money.

Ms. Johnson’s family offered to help her financially, and she put her house on the market. Because of her unemployment, her house and car loans and regular expenses had depleted her savings. In addition, each of her doctor visits had cost in excess of \$200, and she had to pay for any needed medications.

Shortly thereafter, the nurse from the mammography facility called to follow up on her case. When Ms. Johnson indicated that she was trying to raise \$10,000 for her surgery, the nurse instructed her to call the doctor back that very day and get a referral to the M.D. Anderson Cancer Center. Within 45 minutes, she was in the Cancer Center’s care. Necessary tests were done, and her doctor at the Center spent 2 hours explaining treatment options. The doctor explained that since February, the nodule in her breast had increased to the size of a golf ball; she suggested Ms. Johnson consider a clinical trial. She agreed to enroll in the trial and underwent a year of chemotherapy and 6 weeks of radiotherapy. After 2 years, however, Ms. Johnson began to experience new symptoms, and her platelet count dropped as if she were still on chemotherapy. She began to hemorrhage. With medication, her platelet level returned to normal. However, a bone marrow aspiration indicated that while her body was making platelets at a normal rate, they were being destroyed. It was discovered she had leukemia and had probably had it for some time. She was treated and has been disease-free for the past 16 years.

Ms. Johnson also related the story of her second-eldest son, who was told for 2 years that tumors in his chest were benign; in fact, he had atypical cell lung cancer. He was successfully treated at M.D. Anderson Cancer Center.

Ms. Johnson urged cancer patients and those who suspect they may have cancer to fight as much as is necessary for the care they need and deserve. She believes there is nothing that cannot be done if one has enough determination and hope.

DISCUSSION—STATE OF TEXAS

Key Points

- The experiences of the Longs may illustrate how the issues of lack of insurance are exacerbated in a State as large as Texas, in which the Longs had to travel 1,000 miles to find a source of care. Some educational outreach programs exist to try to enlighten the provider community on these problems, but they are insufficient.
- Dr. Slamon expressed his consternation that while Texas is committed to cancer issues and supports its two cancer centers and the Cancer Council, it has no functional cancer registry; he pointed out that the Cancer Council cannot possibly determine whether it is reaching its objectives without an adequate surveillance system. Though the Registry and the Cancer Council are both funded with State dollars, they appear to operate independently of one another. Dr. Weiss indicated that the Cancer Registry is located within and funded by the Health Department. It does not have line-item funding from the legislature, but rather falls under a generic disease prevention and control funding category that has many competing priorities in the State. In this setting, the Registry has not been among the highest priorities. To address these well-recognized issues, a funding initiative that has broad support from the cancer and medical communities is now being proposed to the legislature.
- Legislatures, like the public, need to be educated. Although there may be a risk that the Cancer Council's funding would be cut if the legislature determines that the Council's activities cannot be accomplished without a registry, and the Registry cannot be funded, it is more likely that they will approach the problem more rationally and correct the funding situation. The Council and Registry staff have been working to educate the legislature on this issue, but it will likely take 1 to 2 years to get a funding measure through the State legislature. Dr. Weiss indicated that additional funding from the CDC may be forthcoming; this would help advance the capacity of the Registry. Dr. Slamon invited Dr. Weiss to share the Panel's view of this situation with decisionmakers at the State level.
- Although it is admirable that each State has some capacity to provide charitable care, the real issue is not to expand charitable care, but to find a way to get everyone insured.
- Barely 10 percent of financially eligible women are able to access the CDC Breast and Cervical Cancer Screening Program in West Texas. Statewide, approximately 30 percent are served. West Texas lacks the doctors and facilities to accommodate the need for services. The West Texas mobile mammography unit is the only screening facility available to women in the 12 West Texas counties that does not involve driving 200 miles to the next closest facility. Prior to implementing the van service, mammography services had not been available in the area for 5 years.
- Currently, in El Paso, facilities are closing because of low reimbursement levels. The State of Texas reimburses Medicaid levels at access rates. Because they have smaller populations, rural Medicaid providers are reimbursed less than \$50 for a mammogram. Fifty dollars does not pay for the film, much less the physician who is going to read it and the technician who is going to conduct the test. In addition, Federal standards have to be maintained in rural communities exactly as in urban communities, but rural facilities are paid less. This issue, too, is before the State legislature.

- Unfortunately, Texas does not consider health care a priority. If it did, the State would not be ranked 49th in the United States. El Paso is a community of 600,000 people, and people diagnosed with cancer through the CDC program cannot be seen on a timely basis. The policy at the State medical school, which is connected in El Paso and in Lubbock (the facility that turned the Longs away) is that uninsured patients must pay 30 percent up front or they will not be seen. This access situation is frightening, to say the least. Cooperation with private sector providers is better than that with State-level providers.
- In El Paso, the waiting list and the waiting times for breast and cervical cancer screening are so long that people simply no longer show up for their appointments. Thus, even when women are enrolled in the program, substantial monitoring and followup are needed to get each one seen; these patients cannot repeatedly take time off from work without losing their jobs.
- The paperwork for the Breast and Cervical Cancer Screening Program is burdensome at best. However, it is so important to the community that the Consortium has opted to administer all the paperwork for all the providers with which it contracts (currently 89 percent of the local providers in all of West Texas). Once a patient receives an identification number for the Program, she can be seen in any Program location across the country. Even with this assistance, there are simply too few providers to meet patient needs.
- Each State's Medicaid program sets its own standard of reimbursement for the Breast and Cervical Cancer Screening Program. Texas takes the Medicaid average for the State and reimburses at that level for Pap smears, mammograms, ultrasounds, and diagnostic work. This equates, for example, to \$62 for a mammogram, which probably does not cover the cost of administering and reading the test.
- Paperwork associated with establishing and maintaining Medicaid eligibility is nearly twice as cumbersome as that associated with the Breast and Cervical Cancer Screening Program.

STATE OF UTAH

Presenters:

Ms. Kathryn Rowley

Ms. Maritza Arce-Larreta

Ms. Julien Puzey

Mr. Bruce Ignacio

Ms. Jaquetta Tutor

Ms. Veronica Betancourt

MS. KATHRYN ROWLEY

Background

Utah's population numbers approximately 2,130,000 people, and 76 percent of the population lives within a 100- by 20-mile area. Thus, the majority of the remaining area is classified as frontier (zero to six people per square mile), with some rural areas.

The population in Utah is 95.1 percent white, 0.9 percent African-American, 1.4 percent American Indian/Alaska Native, 2.6 percent Asian/Pacific Islander, and 7.1 percent Hispanic.

As of 1996, almost 70 percent of the population in Utah belongs to the predominant religion, the Church of Jesus Christ of Latter-Day Saints. The religion forbids smoking, drinking, and sex outside of marriage. These lifestyle factors may be significant contributors to Utah's rank as the third healthiest State in the

Nation. The uninsured rate in Utah, as determined by the U.S. Census Bureau in 1999, is 14.2 percent. Utah also ranks high in educational attainment.

Cancer remains the second leading cause of death in Utah. From 1995 to 1999, the State cancer incidence rate was 332 per 100,000 population, with a rate of 387 for males and 291 for females.

Breast cancer stage at diagnosis is remarkably similar across all of the local health districts. The majority of cases are diagnosed at localized stages, with only a small proportion diagnosed with distant disease. Utah has been a leader in this area; its screening program for breast and cervical cancer has been in operation for over 25 years. For the last 7 years, the program has been enhanced with Federal money from CDC.

Five-year relative survival rates for breast cancer vary by stage and local health district to a greater extent than incidence rates. This variation could reflect variations in treatment from one district to another. Utah is ranked 50th in the Nation for age-adjusted cancer mortality rates (1993 to 1997). Utah recently passed the Breast and Cervical Cancer Treatment Act, so treatment for these diseases will now be paid for through Medicaid. Currently, the cost for Utah's Medicaid program to treat a patient with breast or cervical cancer is estimated at \$9,600 a year.

Although Utah does not have a public health screening program for prostate cancer, the State has been relatively successful in detecting these cancers at early stages. Through the American Cancer Society, a program called Men to Men was started, focusing on prostate cancer and its early detection. A much higher percentage of men are surviving with late-stage prostate cancers, which is consistent with national trends. Utah is ranked 19th in the country for prostate cancer mortality.

Utah is doing less well in colorectal cancer detection and mortality. This likely is due to the lack of a screening program for this disease. Very few late-stage colorectal cancer patients are surviving, perhaps because they are being detected too late. In addition, treatment varies by district. Utah needs to find out what can be done in each district to encourage proper treatment. Utah is ranked lowest in the Nation in survival rates for colorectal cancer.

Utah has few cases of invasive cervical cancer (less than 30 cases per year in most health districts), and most of these are being found at local and regional stages. However, there are no 5-year survivors at the distant stage, indicated that more work is needed to detect all cervical cancers at early stages.

Utah is in the process of developing a comprehensive cancer plan for the State. Among the organizations involved are the ACS, the Health Department, the Huntsman Cancer Institute, survivor organizations, and the church community. The goal of the plan is to detect cancer at an early stage, increase the number of people receiving state-of-the-art treatment, and decrease mortality.

Key Points

- Barriers to treatment include travel and travel-related costs, and the inability of farmers and ranchers to leave their farms/ranches for long periods in order to receive treatment. Because their livelihood depends on them being there, they often opt for less treatment than is needed.
- Money is a major barrier to treatment. Uninsured and underinsured people have to be destitute to receive the help they really need.
- Clinical trials need to be offered, and in addition, offered in a positive manner to encourage participation.

MS. MARITZA ARCE-LARRETA

Background

Ms. Arce-Larreta is Clinical Coordinator of the Utah Cancer Control Program, part of the CDC-funded Breast and Cervical Cancer Early Detection Program. The program targets low-income women at or below 240 percent of the State poverty level, both with and without insurance.

Although Utah is a very healthy State, barriers to care exist. Because the program is listed as the Utah Cancer Control Program, Program staff receive many phone calls related to cancers other than breast and cervical cancer.

Key Points

- Lack of provider education about cancer and cancer treatment is an important barrier to appropriate care in Utah. Most providers, particularly primary care physicians in rural areas, have had no formal training about cancer, and there are few surgeons in these areas. The State has offered training on cancer treatment to family practitioners, who have declined because they feel that since they do not provide cancer care, they do not need such training. The State contracts with local health departments to do breast and cervical cancer screening. Typically, registered nurses are trained to perform this screening, but they are not permitted to diagnose. Together, these conditions leave a significant gap in care.
- Many of the screening program's clients, especially rural ones, have little or no access to cancer information. Most are poor, and some are unable to read or write. They do not have access to computers.
- Utah lacks support groups in languages other than English. This is becoming an increasingly important issue because the Hispanic population is growing. The first support group in Spanish will soon be started; in addition to being a source of support, it will be a source of information for Hispanic women and men.
- Many of the Hispanic population have limited education in their native language, and educational materials suitable for them are lacking. NCI's materials are the best available, but materials on cancers other than breast and cervical are needed. In addition to being at the right reading level and including drawings and graphics, educational materials must also be culturally sensitive.
- Some women in the screening program believe that if they are found to have cancer, it is God's will; thus, they should not be treated. Ms. Arce-Larreta has learned to turn this belief around by emphasizing that "it is also God's will that you have found out that you have cancer and we can do something about it."
- Many patients fear that the treatment is worse than the disease. This reflects bad experiences. Much needs to be learned about pain control and controlling side effects of treatment (e.g., mucositis, shingles) in order to lessen this fear. In addition, because of *machismo*, Hispanic men believe they must endure pain without complaint or medication.
- The cost of drugs is an important issue. If patients cannot afford to buy drugs that will make them feel better, they will have very difficult treatments and may avoid treatment.
- Patients' age and comorbidity must be taken into consideration. Research evidence shows that chemotherapy can be used very successfully in older people, but it is often deemed unnecessary because of their age. However, comorbidities may be legitimate reasons to forgo chemotherapy or other treatment.

- The number of people being screened in rural areas of Utah is decreasing. This may be because the registered nurses who do the screening are also responsible for activities related to sexually transmitted diseases, immunizations, family planning, and school nursing. They do not conduct as many cancer clinics as are needed. The State is trying to improve this situation.
- Lack of access to cancer specialists and lack of ambulatory cancer clinics are also problems in rural areas. Utah had a mobile van until several months ago, when the hospital that owned the van discontinued the service because it was not profitable. There are now women in rural areas with no access to mammography or other services. Two other vans exist, but they provide only local service. The issue is not the cost of operating the van, but rather the cost of paying the technicians who operate the equipment and the radiologist who reads the films. The payments available through the Breast and Cervical Cancer Screening Program do not cover these costs.
- Even if available, an important limitation of mobile vans is that they perform only screening mammography. A woman who needs a diagnostic mammogram must be assisted to travel to a major city. If that person works, she has to take time off from work. If she has children, she has find someone to care for her children. If the woman is a Hispanic migrant, she will need an interpreter. She also likely will need transportation.
- Those most disadvantaged are the working poor who work three or four jobs and have no insurance—e.g., waitresses and truck drivers. These are the most underserved population for cancer prevention, cancer control, and cancer care. A major reason the working poor refuse treatment is the cost of drugs. For example, Anzemet[®], an antiemetic, costs \$100 a pill. Zofran[®], another antiemetic, costs \$35 to \$40 dollars a pill. A patient may have chemotherapy at the doctor’s office and then cannot afford a 3-day supply of those medications. They rely instead on medications like Phenergan[®] or Compazine[®], which are inexpensive but do not control the nausea.
- Similarly, the cost of treatment is an issue. New modalities in treatment are more expensive. Is it realistic to inform people about treatments they cannot afford? In one case, a rural provider found a small ductal carcinoma in a patient’s breast. Because the patient would be unable, for cost and logistical reasons, to comply with a radiation therapy regimen, she received a mastectomy. The patient was educated as to the choices and agreed with the treatment. Still, because of cost considerations, she lost a breast.
- Utah has recently passed legislation to participate in the Breast and Cervical Cancer Treatment program. Ms. Arce-Larreta expressed concern as to whether women will actually “automatically qualify for treatment,” as the legislation states. Delay or inability to qualify for State-funded programs has been a problem in the past.
- Many cancer patients cannot afford to stop working. They worry about leaving their families bankrupt, and this is a major reason that the working poor quit treatment. Ms. Arce-Larreta recounted the story of a breast cancer patient diagnosed through the program who quit treatment after a month and a half because she incurred a bill for her Medicaid copayment of \$186.22. Since she made only \$1,200 per month, of which \$500 was needed for rent and utilities, this bill made treatment unaffordable. Cancer treatment services must be made accessible and affordable for all patients.

MS. JULIEN PUZEY

Background

Ms. Puzey is an Advocacy and Spirituality Coordinator at the Cancer Wellness House, Salt Lake City. Her father died of cancer in 1963. Her mother had leukemia for 11 years and developed breast cancer while she was being treated for the leukemia. Ms. Puzey’s sister is a 12-year cancer survivor, and 30 cousins currently have cancer. Ms. Puzey was herself diagnosed with ovarian cancer in 1999.

Key Points

- In a graduate school course on models attended by Ms. Puzey, it was proposed that a problem does not exist unless there is a reality–expectation gap. That is, if one is not clear about what the expectations are, nor clear about the reality, one has only issue after issue, not a problem. If it exists, what is that gap in the American system? It seems that the expectation verges on paternalism: that we are going to be taken care of, and taken care not only equally, but as if each of us were the favorite child. That is a high expectation. Further, the expectation seems to be that if everyone was insured, all health care would suddenly be affordable. This reality is questionable.
- Seventy years ago (the generation of the grandparents of current baby boomers) the time from diagnosis to death for a major illness was 2 months. A person was diagnosed, got sick, traumatized the family one time, and died. The current statistics for baby boomers are that the time from diagnosis to death for any major illness is anywhere from 7 to 11 years with 4 years of disability. Fifty million baby boomers are just about stepping through that window, and no infrastructure exists that is prepared to handle 11 years of chronic morbidities and 4 years of disabilities for those 50 million people.
- There is a very big difference between treatment and care, and it seems that we expect treatment to bring care. For example, there are television ads for tamoxifen, which is kind of like the Rogaine[®] of cancer medications. This may be the first time that people are being asked to buy a prescription drug to treat themselves for a condition they do not yet have. Similarly, television ads for Procrit[®] suggest that if a person gets the treatment, it will come with a whole package of wonderful loving people with a whole support system behind them. Sometimes people demand treatment because they are disappointed that the care they expected was not there. A diagnosis of cancer is very much like having the roof blown off your house. When there is a tornado, the Federal Emergency Management Administration (FEMA) shows up the next day, and they start the reconstruction process. Conversely, when a person is diagnosed with cancer, it is as if FEMA had shown up with a piece of Visiclean[®] and four bricks and said, “Throw this over your head for shelter and be very hopeful, because there’s somebody up there on that hill who’s doing a whole lot of research on roofing materials, and at any minute, they could find just the perfect roofing material that will keep the roof from blowing off anybody’s house again.” However, when the rain is coming down on your head, you really don’t care about roofing materials.
- We need to be clear about our expectations and our reality. When people are given reality, they make appropriate choices. When there is a flood or snowstorm, everybody in the neighborhood knows what to do because there is shared intent. To continue the metaphor concerning cancer, the roof is not just blown off one person’s house; it is blown off of all of our houses. We are pretending that what happens to one person is not happening to all, and that is simply not the case.
- We need to begin educating people about cancer as a chronic condition. In general, cancer still is viewed as acute and deadly. However, it is now more often chronic and treatable—and chronic and treatable—and treatable and treatable. But treatment involves carcinogens, of which one likely side effect is another cancer. People need to understand that in treating cancer as a chronic condition, there are no quick fixes. Cures are about stopping a process. The notion of cure is very different for the general public than it is for the medical profession. For the medical profession, a cure means that a person will have the same life expectancy as he or she would have had if that person had not had cancer. It does not necessarily mean that one will be cancer-free. “Cure” from cancer does not usually mean eradicating cancer, but rather extending longevity.
- Care is subjectively experienced as being seen as addressing the whole person. Treatment, by its very nature, focuses on the part (sometimes at the expense of the whole). The goal of treatment is, appropriately, to cure the cancer or delay the progression of the disease. Caring supports natural healing and reinforces our intrinsic human wholeness.

- Many cancer treatments are extremely expensive. Some of the treatments Ms. Puzey received cost \$10,000 each. Though she is grateful to have received this care, she wonders about the morality of this expenditure on a single individual, given health care needs worldwide.

Recommendations

- Care and treatment need to be given equal weight in the funding equation. Until care and treatment are experienced as equal partners in a seamless process, individuals and families living with a history of cancer will continue to express dissatisfaction with our health “care” system.

MR. BRUCE IGNACIO

Background

Mr. Ignacio, age 51, is a Community Health Advocate from the Uintah and Ouray Ute Tribe of Utah in Fort Duchesne. In this capacity, he speaks for the health needs of the tribe, particularly when they are seeking care outside the tribal community.

The membership of the tribe totals 3,163, with ages ranging from newborn to 99 years. Seventy-three percent of the population is under age 40. As of 1990, average life expectancy in the tribe was 55 years; thus, conducting cancer research in this population is not feasible.

In the northeastern part of Utah, 70 percent of the tribal population is unemployed, based on State data; the unemployment rate is 77 percent according to information received from the Ute tribal employment office. Of the working Ute membership, 12 percent are below the national poverty level. There is only a small middle class among the tribe.

In the 1970s, a Tribal Health Board was formed on the Ute reservation; it was a politically appointed group of individuals chosen by the Tribal Business Council. Its first business was to communicate with the IHS. Later, its activities expanded to include the area office in Phoenix, Arizona, and later still, to include the Business Council itself. Recently, the Tribal Health Board has begun to interact at the State level.

Key Points

- Since 1991, there have been 34 confirmed cases of cancer among the Ute; however, this number is questionable, since there are no data to confirm it. The Indian Health Clinic on the reservation is the main source of care for tribal members. For special care, people are given referrals in two of the local communities—Roosevelt and Vernal, Utah—towns with predominantly non-Native communities. Tribal members had not been treated with dignity and at times, they were not allowed to be admitted to the hospitals. For the past 4 or 5 years, Mr. Ignacio has been advocating for the tribe with these facilities.
- Indian Health Service funding has decreased from 57 percent to 51 percent in the past 3 years. This is due in part to increases in users and to the higher cost of health care. On the Ute reservation, no one with cancer is turned away from treatment, but that means that someone else will have to be denied health care.
- Of the tribal members who are employed, only 15 percent carry health insurance, and premiums are rising. Many, including Mr. Ignacio, face a decision as to whether to continue coverage. Of the tribal members who do carry health insurance, most continue to use the IHS facilities for health care rather than go outside that system to acquire private health care. This may be because they are simply more familiar with the IHS system.

- Western medicine is relatively new to the Ute people; until the 1970s, people went to the doctor to mend a broken leg, for childbirth, or for common things like influenza and ear infections, but they never went to the doctor for things like cancer and diabetes—the things that are ravaging the reservation now. Belief in spiritual healing still exists and is a vital part of the tribe’s existence and reality that should be respected. Whether it saves lives or not is not the question.
- Language has been a barrier to care for some Ute people being treated in hospitals. Twenty-five percent of the tribal membership are fluent Ute speakers for whom Ute is their first language. This segment of the population does not understand English and requires an interpreter in a medical situation. Mr. Ignacio approached some of the doctors at the local hospital about the need for interpreters. Some of them were receptive to the idea; others rejected it outright. Mr. Ignacio also approached the Tribal Health Board, but to date nothing has been done to help meet this need.
- We cannot forget that people deserve dignified health care.

MS. JAQUETTA TUTOR

Background

Ms. Tutor, from Richfield, Utah, was a cook for 35 years. In 1992, she began to feel unwell. She went to several doctors who gave her varied explanations and medications and sent her home. She kept working and persuaded herself that nothing was really wrong.

In 1998, she changed doctors again. The new doctor told her that she was seriously ill but could not be treated locally. He referred her to a specialist in the northern part of the State. However, Ms. Tutor lacked the funds to travel to and access this care, so she sought assistance from the State and other agencies to enable her to take time off from work long enough to receive treatment. She was repeatedly denied Medicaid coverage. Finally, her doctor called the Medicaid agency and indicated that she would have to be off work for at least 3 months to have surgery. Because she had a grandson living with her whom she supported, she was approved for assistance to have her first surgery. She was diagnosed with uterine cancer and had a hysterectomy. She was told that all cancerous tissue had been removed. Ms. Tutor returned home.

Two weeks later, she was in severe pain. She had taken the antibiotics she had been given, but she did not like to take pain medication. She was taken by ambulance back to the hospital, where she was found to have an abscess at the surgical site. The abscess was removed, and she was again sent home. Ms. Tutor returned to work, but about a month later began to have more problems. She could not seem to get well.

She was sent back to the facility in the northern part of the State and was found to have two more abscesses. One was removed, but she was told she would have to return to have the second one removed. She returned home, but the next night was sick and vomiting. She was again taken by ambulance to the hospital, where the other abscess was removed. She was scheduled to come back in 3 months for a CAT scan to make sure no other abscesses developed. When she returned in 3 months, she was still losing weight and was anemic.

The CAT scan revealed a spot on her kidney, and further tests indicated extensive cancer. Ms. Tutor’s physician told her that she would need surgery and chemotherapy, but that her prognosis was very poor. She was again referred to the facility in the northern part of the State. Her kidney was removed, and she was scheduled for CAT scans every 3 months.

After the most recent scan in January 2001, a cancerous spot was detected on her chest. It was removed in outpatient surgery, but she was called the next day to return to the hospital. The cancerous area was larger

than originally thought, and additional surgery was required. This surgery was performed 2 days later. At this point, Ms. Tutor had undergone seven surgeries in 2 years.

Her doctors told her that she could no longer work because of her health problems. Ms. Tutor applied for Supplemental Security Income (SSI) since she was still supporting her grandson, but she was denied. She was advised to reapply and did so, but was denied again. Three specialists from the facility at which she was treated have provided letters saying that she cannot work again because of her cancer and that it is likely to recur. She again reapplied, and is now awaiting an eligibility decision from SSI.

MS. VERONICA BETANCOURT

Background

Ms. Betancourt lost her daughter, Sophia, to cancer. Sophia was premature at birth, weighing 1 pound 3 ounces and measuring 12 inches in length. Shortly after birth, a lump, referred to by her physicians as a noncancerous blood tumor, was found on her liver. However, the doctors said the mass was behaving and growing like a cancer, and it was treated as if it were cancer. Despite lengthy treatment that included steroids, coil treatments to cut off the tumor's blood supply, and radiation therapy, the tumor grew over time to the size of a basketball, weighing 5 pounds. Sophia had to be fed intravenously. Ms. Betancourt recounted the heartbreak of her daughter begging for a single bean and grain of rice, just to be able to taste real food. Eventually, Sophia could not eat or breathe and was put on life support.

Sophia's situation became grave; she required an immediate liver transplant. However, since the chance of getting an organ in Utah was relatively small because of its sparse population, Mrs. Betancourt and her daughter were flown to Chicago. She received a transplant in the nick of time. A few days later, she developed seizures, a side effect of the cyclosporin she was being given to prevent transplant rejection. Ms. Betancourt, who by this time had educated herself about her daughter's condition and care, asked the doctor to change her medication to Prograf[®] (also known as FK506). The doctor refused, saying that he was the doctor, while she was just the mother. When the doctor would not be persuaded, Ms. Betancourt sought out a neurologist at the hospital and asked that he evaluate Sophia's condition. The neurologist recommended that she be taken off cyclosporin and given phenobarbital. This intervention by the neurologist caused the liver doctor to be even more hostile to Ms. Betancourt.

Ms. Betancourt could tell that Sophia was still not doing well. She asked for a conference of the physicians and nurses treating the child. Subsequently, one of three spinal taps yielded a single atypical cell. The doctors said they would just monitor Sophia closely. At this point, Ms. Betancourt decided that she wanted to return with Sophia to Utah to have her treated at the University Medical Center in Salt Lake City.

After returning to Utah, Ms. Betancourt's younger child, a boy, became ill with a testicular growth. This was eventually found to be fluid-filled and not dangerous, but at one point, both of her children were in the same hospital.

Four days short of the 1-year anniversary of her liver transplant, Sophia was diagnosed with a tumor above her left eye. Prior to the diagnosis, however, Ms. Betancourt was accused of abusing her child. Unknown to her, Sophia had bumped her head at school. She was attending school despite having feeding tubes and other visible medical apparatus. Sophia received radiation to her forehead for the tumor. It burned badly, and the cream prescribed for the burns cost \$45. Medicaid would not cover this medication. At the time, Ms. Betancourt was supporting her family on \$504 per month. At one point, she was nearly evicted from her apartment—until her landlord learned of her situation.

More than 15 tumors were subsequently found in Sophia's lower spine and lungs. She had a seizure due to pressure from the tumor behind her eye. It was drained, and for a short time, Sophia did better. But the tumor later hemorrhaged, destroying most of her brain function, and she was put on life support. After being assured that Sophia would not be in pain, Ms. Betancourt made the decision to cease life support and herself turned off the machines. Sophia lived another 8 hours.

Ms. Betancourt cited the need for education so that people with cancer can reach treatment early and have improved chances for survival and better quality of life. She entered into the record the following, written the previous day as she was listening to the testimony of other speakers at the meeting:

Cancer has no heart. But when our loved ones are diagnosed, the hearts of mothers, fathers, family and friends do hurt.

It knows no feeling. But the ones with the disease have pain.

It has no soul. But when our loved ones die, their souls are taken.

Cancer has no face or racial differences or religion. It can affect us all. It is ageless.

It knows no boundaries. It's all over the world. It's like the wind. It's all around you, and it goes everywhere regardless of where you are.

It has no value, but care and treatment are expensive.

DISCUSSION—STATE OF UTAH

Key Points

- Mormons are said to have a lifespan about 6 years longer than any other American population and the lowest cancer incidence and mortality of any identified American group. If this is true, it likely reflects lifestyle factors (no smoking or alcohol consumption; many have vegetarian diets). Several studies of these factors are underway or planned.
- Members of the Ute tribe who are employed by the tribe have insurance available to them; this insurance is also available to employees who are not Indians. The 15 percent insured figure cited by Mr. Ignacio referred to Ute tribal members who participate in insurance programs made available to them through other employment. The IHS bills the insurance companies for services provided to insured persons who continue to use IHS facilities.

CLOSING REMARKS—DR. HAROLD FREEMAN

As Dr. Freeman began his remarks, it was clarified that to be classified as rural, an area must have a population density of from 6 to 99 people per square mile. It was also stated that transcripts of the meetings are available upon request. In addition, speakers or others who wish to submit additional testimony in writing are invited to do so.

Dr. Freeman thanked the speakers for their participation and highlighted the day's presentations. He indicated that the Panel will hold one more regional meeting, in Washington, DC, after which the Panel will prepare a report to describe in the most comprehensive and sensitive manner possible the many issues it has heard throughout the Nation. These findings and recommendations will be presented to the President of the United States.

I certify that this summary of the President's Cancer Panel meeting, *Real People, Real Problems—Why Don't All Americans Get the Best Available Cancer Care?*, held March 8–9, 2001, is accurate and complete.

Certified by: Harold P. Freeman Date: 07/12/03

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