

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?

September 14–15, 2000
Burlington, Vermont

OVERVIEW

The President's Cancer Panel was chartered to monitor and evaluate the development and execution of the National Cancer Program (NCP) and report to the President on barriers to Program implementation. This meeting was the second in a series of regional meetings to explore issues that affect the ability of communities to provide cancer care—including prevention, education/communication, detection, treatment, diagnosis, rehabilitation, and palliative and end-of-life care—to people in the diverse neighborhoods of the Nation. This meeting brought together representatives from seven States in the New England/New York region to discuss these issues, the barriers faced at local levels, and local and State-level efforts to address them. The State delegations, composed of up to five individuals, also 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.

National Cancer Institute

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

Speakers

Susan Anderson, R.N., Director, Clinical Trials Office, Yale Cancer Center (Connecticut)
Mary Ann Andries, Community Representative (Rhode Island)
Mark Baptiste, Ph.D., Director, Bureau of Chronic Disease, Epidemiology and Surveillance, New York State Department of Health (New York)
Carol Beagan, Community Representative (Maine)
Nancy Berger, M.P.H., Director, Health Education and Intervention, Connecticut Department of Public Health (Connecticut)
Penny Blazej, Coordinator, Center for Hope (Connecticut)
Patricia Brennan, M.S., Director, Office of Research, Bureau of Family Health, Massachusetts Department of Public Health (Massachusetts)
Nadine Bullion, L.C.S.W., Manager of Support Services, CancerCare of Maine (Maine)
Sheila Callan, Community Representative (Vermont)
Jan Carney, M.D., Commissioner of Health, Vermont Department of Health (Vermont)
Ann DelleDonne, Community Representative (New York)

Dennis Derman, M.D, Lemuel Shattuck Hospital (Massachusetts)
Richard Farrell, Community Representative (New York)
Linda Fisher, R.N., Community Representative (Connecticut)
John Fulton, Ph.D., Director of Chronic Disease, Rhode Island Department of Health (Rhode Island)
Denis Hammond, M.D., New Hampshire Oncology/Hematology (New Hampshire)
Barbara Kitzmiller, Community Representative (Vermont)
Barbara Leonard, M.P.H., Director, Community Health Programs, Maine Bureau of Health (Maine)
Rosemarie La Gasse, M.Ed., Director, Women's Health Initiative, YWCA (Maine)
Jacques Lipson, M.D., Community Representative (New York)
Geraldine Malter, Community Representative (Massachusetts)
Janet McGrail, Director, Cancer Prevention/Elder Health, Boston Public Health Commission, (Massachusetts)
Marilyn Moore, Program Director, Witness Program (Connecticut)
Arlene Munn, Frisbie Memorial Hospital (New Hampshire)
Kay Perkins, Community Representative (Vermont)
Larry Pizzi, Executive Director, The Brain Tumor Society (Massachusetts)
Laurie Rosa, R.N., Cancer Care Education Coordinator, Portsmouth Regional Hospital (New Hampshire)
Sue Sgambato, Community Representative (Rhode Island)
Marguerite Stevens, Ph.D., Community Representative and Associate Professor, Community and Family Medicine, Norris Cotton Cancer Center (New Hampshire)
Laurie Storey-Manseau, American Cancer Society (New Hampshire)
Deborah Travis, Community Representative (Vermont)
Martha Wells, New Hampshire Department of Health and Human Services (New Hampshire)
Bertram Yaffe, Founder, Ernie Yaffe Foundation (Rhode Island)
Jerome Yates, M.D., Ph.D., Senior Vice President, Population Sciences and Health Services Research, Roswell Park Cancer Institute (New York)

DAY 1

OPENING REMARKS—DR. HAROLD FREEMAN—CHAIR, PRESIDENT'S CANCER PANEL

On behalf of the Panel, Dr. Freeman thanked the Vermont Cancer Center for hosting the meeting. He indicated that Dr. Dennis Slamon was recently appointed to the Panel by the President, replacing Dr. Paul Calabresi, who served for approximately 5 years. Dr. Freeman thanked Dr. Calabresi for his work with the Panel and for his continued support of the Panel's work.

Dr. Freeman further indicated that:

- The meeting in Vermont is one of a series of seven U.S. regional meetings; in addition, a meeting with an international focus is planned for June 2001. The concept for these meetings grew out of the conclusions of the Panel's 1999 report, which evaluated the history and current status of the National Cancer Program (NCP) and considered how the national effort against cancer should move forward to more rapidly reduce the burden of the disease. The report acknowledged the real and substantial progress that has been made against cancer and stressed that far more resources should be devoted to the discovery process. The NCP has evolved into a highly successful research program that should continue to be fully supported.
- There remains, however, a critical disconnect between discovery (the research enterprise) and delivery (the provision of cancer care). Continuing concerns include: cancer care and cancer outcome disparities among populations; insufficient emphasis on patient outcomes; lack of consensus as to what constitutes quality cancer care; risk-promoting lifestyles; and a variety of public and private sectors and groups that do not acknowledge their roles in the cancer problem.

The Panel has made the following recommendations:

- Barriers that prevent the benefits of research from reaching all populations must be identified and removed.
- It is the responsibility of legislators and policymakers to enact laws and policies to ensure access to quality cancer care for all.
- Mechanisms are needed to ensure that public and private health care payers have access to and understand evidence for health care interventions and incorporate them appropriately into standards of cancer care.
- Awareness of the cancer problem, as well as current knowledge about prevention and all aspects of care, must be increased through culturally appropriate public and professional education.
- Public pressure must be brought to bear in recruiting to the national cancer effort sectors that have not traditionally perceived themselves as having a role in the cancer problem.
- The current and future cancer workforce requires greater training in state-of-the-art cancer prevention and care, and this workforce must better reflect the diversity of the population and be more sensitive to cultural issues.
- The equal importance of the research and delivery components, and the current disconnect between them must be recognized. Overcoming this divide requires concerted action by all stakeholders. If we do not better connect the research and delivery enterprises, our progress against cancer will continue to be slow, uneven, and incremental. This is not just a medical and scientific challenge, but a moral and ethical challenge for the Nation.
- The Panel has asked the participants at this meeting to join in identifying what is required to ensure that the public receives the benefit of research conducted through the NCP. Toward that end, the Panel has posed the following questions to all speakers:
 - What is the disconnect between research and the delivery of proven cancer interventions in your State? Why does this deficiency exist?
 - Who is underserved for cancer prevention and cancer care in your State? Who are the vulnerable populations?
 - What is stopping people with treatable cancer from receiving the most appropriate treatments? Why are people dying of treatable cancers?
 - In addressing local and regional cancer issues, how have the economic, political, and public will been marshaled successfully? What problems could not be overcome?
 - What do States and communities need to do to provide proven interventions for cancer prevention, cancer control, and cancer care at the neighborhood level to people with cancer and those at risk for the disease?
 - What can or should be done at the national level to support local/regional efforts?
 - What policy, legislative, and infrastructure changes are needed at the State, local, and national levels?
- The Panel is in Vermont to learn, not to teach. All of the testimony and other input received at the meeting and Town Meeting will be used to develop a report to be presented to the President of the United States in approximately 18 months. In addition to input received at the regional meetings held in the United States., the Panel also plans an international meeting to learn about the barriers and

successes experienced by other nations as they deliver cancer care to their populations. This information will also be integrated into the Panel's report.

- In addition to the State presentations, this meeting will include an opportunity for the public to present questions or comments to the Panel in a Town Meeting to be held in the evening and moderated by Steve Zind of Vermont Public Radio's *Switchboard* program. The Town Meeting will be broadcast live, and listeners will be invited to call in to address questions or comments to the Panel.
- Dr. Freeman acknowledged the efforts of Dr. Maureen Wilson, Executive Secretary of the Panel, for her efforts and those of her staff in organizing and convening the meeting.

DIRECTOR'S REPORT—DR. JON KERNER, NCI

Dr. Kerner expressed his appreciation for the Panel's work and the warm welcome provided by the Vermont Cancer Center. He indicated that:

- NCI is working to finish awarding grants comprising the majority of its \$3.11 billion budget to extramural researchers before the end of the fiscal year. The trend of increased investment in cutting-edge science is likely to continue in FY2001, helping to achieve NCI's fundamental goal of developing interventions that reduce cancer incidence, morbidity, and mortality.
- The return on the national investment in cancer research has been significant. From 1992 to 1997, the rate of new cancer cases declined 1.3 percent. The cancer death rate decreased 0.6 percent per year between 1991 and 1995, then accelerated to a 1.7 percent decrease per year from 1995 to 1997. However, we need to find ways to expand this progress further and to address issues raised by the Panel. Despite the fact that more cancer patients are living longer with better quality of life, cancer remains a major public health problem and burden in this country. This burden continues to be borne unequally by different population groups across the Nation.
- NCI's efforts to address cancer-related health disparities are part of a larger effort, both at the National Institutes of Health (NIH) and the Department of Health and Human Services (DHHS). DHHS has set a goal to eliminate health disparities of all types by 2010. In support of this goal, NCI has created a new investment challenge specifically addressing cancer-related health disparities. Activities will be directed through a new Center, to be headed by Dr. Freeman, within the Office of the Director and will focus on the historical differences between population groups, the impact of socioeconomic status and other factors on health disparities, and other areas. It is anticipated that findings from this research may have important health policy implications, the implementation of which will require collaboration with the policy arms of government.
- New investments will be made in fundamental research to identify the broad social determinants of cancer health disparities. For example, NCI will develop Centers for Population Health; planning is already underway in collaboration with the National Institute on Environmental Health Sciences (NIEHS) and the Robert Wood Johnson Foundation. In addition to individual risk factors, these Centers will study community-related factors such as residential segregation and other factors that may inadvertently contribute to cancer health disparities.
- New intervention research will focus on tobacco, diet, physical activity, and cancer screening to understand how differing access to and utilization of these services and lifestyle factors may contribute to current disparities. Surveillance of cancer disparities will be strengthened by enhancements to the NCI's Surveillance, Epidemiology, and End Results (SEER) cancer registry program. The number of SEER sites will be increased, and a Memorandum of Understanding has been developed with the Centers for Disease Control and Prevention (CDC) to link SEER with the CDC's National Program of Cancer Registries (NPCR).

- In March 2000, NCI launched the Special Population Networks initiative, its first major investment in community-based cancer center partnerships to research infrastructures with academic centers. Eighteen centers around the country have been designated, based on the idea that community infrastructure is necessary to support community participation in all aspects of cancer research. Communities need to have a voice in determining what research is conducted and a stake in how research results are applied.
- In the coming year, NCI will initiate a program to be called Translating Research Into Improved Outcomes (TRIO). The program will have three components. The first of these will focus on improving the dissemination and use of surveillance data by users at the community level to motivate and support action. Data are available from a variety of Federal, State, and local sources. For example, at the NCI Web site (www.cancer.gov) users can find county maps of the United States showing cancer mortality trends from 1950 through 1974. The Health Resources and Services Administration (HRSA) has county-specific and comparison data for a variety of community health measures (www.communityhealth.hrsa.gov).
- The second component of TRIO will focus on promoting the adoption of evidence-based interventions by making the research evidence available to service providers and policymakers in a format that maximizes the likelihood that they will use the evidence to deliver proven interventions. Investigators who have R01-funded cancer control interventions that have shown efficacy over the first 3 or 4 years of the project will be able to apply for 1 year of supplemental funding to explore how to disseminate and diffuse that intervention in the community. The absence of this support has contributed to the gap between discovery and delivery. In addition, NCI is working with the CDC, the American Cancer Society (ACS), the Agency for Healthcare Research and Quality (AHRQ), and HRSA to provide research evidence in formats that are useful to providers and policymakers.
- Through TRIO's third component, NCI will facilitate local and national partnerships to identify and address infrastructure barriers to delivering effective interventions. These activities will also be conducted in collaboration with the ACS and CDC.

WELCOME—DR. DAVID YANDELL—VERMONT CANCER CENTER

Dr. Yandell welcomed the participants and the Panel and expressed particular appreciation to the cancer survivors participating in the meeting. He also noted that:

- The Vermont Cancer Center is a matrix-based, NCI-designated Comprehensive Cancer Center that operates in partnership with the University of Vermont College of Medicine and Fletcher Allen Health Care. As the only academic center in the State, it serves as a medical Center of Excellence and rallying point for diverse activities in cancer research and care.
- The Panel is to be commended for emphasizing at these regional meetings the testimony of cancer survivors, lay advocates, and families of survivors, whose perspective often is not heard as richly in such settings as that of medical professionals, administrators, and researchers.
- Recent cancer registry data indicate that there are geographic variations in cancer incidence in Vermont. For example, women have an unusually high incidence of colorectal cancer, particularly in some farming parts of the State. Possible environmental factors affecting such cancer rates need to be explored.
- Colorectal cancer is in many instances a preventable disease. Most people in Vermont, as in other States, are diagnosed because they have symptoms, but many cases could be detected earlier and have better clinical outcomes if people were screened as recommended.

- Translating research findings into public health interventions is vitally important; some cancer research has been done in the abstract for a long time and needs to be translated into product. The new NCI programs described by Dr. Kerner will help bring discovery to the public.

REMARKS—MS. LIZ DALEY-JEFFORDS

- Ms. Daley-Jeffords first learned the word, *cancer*, when she was 9 years old and overheard neighbors discussing her mother's cancer. Their tone of voice frightened her. Though her mother survived her cancer, Ms. Daley-Jeffords' sister, brother, and a niece all have died from the disease. Another niece and nephew have been treated successfully and remain cancer-free.
- Ms. Daley-Jeffords was diagnosed with ovarian cancer 3 years ago and was treated at the Rutland Regional Medical Center. She received enormous support from both her medical team and other ovarian cancer survivors.
- Women no longer whisper about their cancers; instead, they now speak openly about cancer and their concerns. They urge other women to take charge of their health and demand to be treated as equal partners in their health care.
- Many Canadian women come to Vermont for cancer treatment; Ms. Daley-Jeffords visits with them whenever possible. She is also uplifted by the courage of a good friend who is now living with ovarian cancer.
- One of the most important things we must address in our society is how to provide people with a good death.
- We should be grateful for the good things in life and work to improve things where it is possible to do so. We must strive to learn more about cancer in order to be better informed and better able to treat and beat the disease

VERMONT

Presenters:

Dr. Jan Carney
Ms. Deborah Travis
Ms. Kay Perkins
Ms. Sheila Callan
Ms. Karen Kitzmiller

DR. JAN CARNEY

Background

As it is in the Nation as a whole, cancer is the second leading cause of death in Vermont. Each year, more than 2,600 new cancers are diagnosed, and more than 1,100 Vermonters die from the disease. Nearly 60 percent of new cancers are diagnosed in people aged 65 and older. For women in Vermont, lung, breast, and colorectal cancers are the leading causes of cancer mortality; among men, lung, prostate, and colorectal cancers cause the most cancer deaths.

Key Points

- Vermont has used surveillance data to help establish goals and measure success relative to the *Healthy People 2000* and *2010* objectives. Cancer has been identified as a top priority for public

health in Vermont. Much of the emphasis has been placed on prevention, early detection, and access to care. Nationally, it is estimated that about half of all cancers can be prevented through smoking cessation and improved dietary habits. In addition, scientific evidence suggests that screening and early detection for cancers of the breast, cervix, and colon/rectum can further reduce cancer deaths.

In the late 1980s, Vermont's death rate from breast cancer was reported to be one of the highest in the country. The Vermont Coalition for Cancer Prevention and Control was formed, comprising non-health professionals, consumers, nonprofit organizations, cancer survivors, and others. Using NCI funds, Vermont women were surveyed to identify barriers to receiving regular clinical breast examinations (CBEs) and mammograms. The predominant reason women were not following screening recommendations was lack of awareness of the importance of these tests. A public awareness campaign was launched in 1991, with good results. Data showed that awareness was much improved and screening rates improved, but a disparity remained in access for women of limited income and education. These data provided the foundation for the next step: formation of Ladies First, a program offering free mammograms and Pap tests along with transportation for limited-income women aged 40 to 64. The program, begun in 1995, has served 3,500 Vermont women to date. Mammography rates among lower-income Vermont women increased from 57 to 68 percent over 3 years. Among all Vermont women ages 40 and older, 73 percent have had a mammogram in the past 2 years; this exceeds the national average. Most importantly, breast cancer deaths in Vermont have declined significantly since 1990.

- Improving access to health care has also been a top priority for the past decade. Vermont has made huge strides in improving insurance coverage for its citizens; more than 95 percent of children are insured, and 93 percent of the population overall have some form of insurance. Two State health programs, Dr. Dinosaur for children and the Vermont Health Access Plan for lower-income working adults and their families, have been instrumental in expanding coverage.
- Prior to developing its 1999 State health plan, Vermont sent public health nurses throughout the State to interview more than 3,000 people regarding how Vermonters' health could be improved and to ascertain the barriers to improving health. Interviewees expressed broad support for emphasis on primary preventive care. Many of the barriers cited related to the rural nature of the State: a fragile supply of health professionals in some communities, lack of transportation, and lack of knowledge about when and how to access care. The widespread transportation barrier is now being addressed in part through the ACS Road to Recovery program, which transports cancer patients to treatment. Established in five counties, the program is expanding.
- Vermont has also been working to improve health care quality. A broad-based coalition is dedicated to the continuous improvement of health care services. Recent cancer-related initiatives include: efforts by the State chapter of the American College of Surgeons to improve care for people with colorectal cancer, release of the first comprehensive Vermont cancer registry report, the Dartmouth-Hitchcock Comprehensive Breast Program, and ongoing efforts of the Vermont Mammography Registry.
- Vermont has benefited from strong policy support from its congressional delegation and its Governor and legislators. Legislative and policy changes in the past decade have included legislation to create the cancer registry and require insurance coverage for mammography. Resolutions have been passed related to family education about breast cancer and increased funding for pancreatic cancer research.
- Public health officials, health professionals, researchers, nonprofit organization advocates, and others have worked with the Governor and legislature to pass some of the toughest tobacco laws in the country. Vermont is dedicating more than \$10 per capita of its tobacco settlement funding to a comprehensive tobacco prevention and cessation program and has launched an initiative to cut smoking rates in half by 2010.

- Ongoing collaboration with the University of Vermont, Vermont Cancer Center, and Office of Health Promotion Research is helping to translate research into practice. For example, Vermont doctors are being trained in CBE, counseling to promote healthy diets, and applying tobacco research to practice.
- Though 85 percent of Vermont women aged 18 and older have had a Pap test in the past 3 years, greater early detection and treatment efforts are needed. An average of 13 women per year still die from cervical cancer.
- Colorectal cancer is the second leading cause of cancer death in Vermont (after lung cancer). Increasing the percentage of adults screened for the disease is another important focus of the Department's efforts. Both health professionals and patients are uncomfortable talking about colorectal cancer, and there is much to be done to reach all Vermonters with lifesaving prevention messages about the disease.
- Minority health advisory committees have identified access to health care as a major issue. In the Latino community, improving access to preventive services has been established as a priority for action. The Ladies First program is a special effort to reach out to minority communities in the State. Outreach messages on television and in print are in multiple languages, and screening enrollment is done over the phone to ease access for those with low literacy.
- Lung cancer is the second most common cancer in Vermonters and the leading cause of cancer death. The American Indian Health Advisory Committee has identified youth and adult tobacco addiction as a priority. The State's overall goal to reduce lung cancer deaths focuses on reducing tobacco use through widely available and affordable state-of-the-art cessation programs and youth tobacco use prevention efforts.
- Reaching all communities with proven interventions and effecting change at the local level hinges on information and partnerships. Vermont takes a community approach to providing information, regardless of how the community is defined (e.g., county, school district, health service area). Local smoking and screening rates are far more helpful to communities in planning and priority setting than State or national data. In Vermont, it is understood that fighting cancer is a huge undertaking; success is possible only by involving health professionals, researchers, public health workers, legislators, citizens, cancer survivors, and many others. For example, hospitals work in partnership with human services and public health agencies and with statewide efforts to improve health care access and quality. Where substantial progress has been made, it has always been the result of a team effort focused on a common goal.

Recommendations

- Better research is needed on prostate cancer and its early detection. Prostate cancer is the second leading cause of male cancer death and the most frequently diagnosed cancer in Vermont men.
- Federal assistance would be welcomed to continue development of and make available to the public clear and current information about cancer prevention, early detection, and treatment.

MS. DEBORAH TRAVIS

Background

In July 1999, Ms. Travis' 14-year-old son, Thomas, was diagnosed with acute lymphoblastic leukemia (ALL). At diagnosis, his white blood cell count was over 500,000, and the cancer had invaded his entire blood system, brain, and spinal fluid. Once stabilized, Thomas began aggressive chemotherapy with the goal of achieving remission from the disease. The high-risk protocol, which included spinal chemotherapy, was provided primarily on an outpatient basis.

Further testing showed that Thomas had a very rare form of T-cell leukemia with a genetic translocation. This type of leukemia is highly aggressive; it typically occurs in infants and has a 75 to 95 percent chance of relapse and death. Moreover, Thomas had a number of risk factors that suggested a particularly poor prognosis. The Traveses refused to accept this prognosis and began a national and international bone marrow donor search to enable the recommended bone marrow transplant. Friends and family ran four marrow donor drives with the assistance of the U.S. Postal Service.

The search for a donor was complicated by the fact that Thomas is adopted, and thus, little was known about his biological family history. When it was discovered that he also had a rare blood antigen profile that would make it extremely hard to find a donor match, his adoption files were opened, and family members were contacted for testing. Even after this step, the closest match was far less than ideal; a mismatched marrow transplant could be more dangerous than the disease itself.

Fortunately, Thomas went into remission, and the Traveses decided not to do the transplant unless he relapsed. However, they explored how donor stem cells could best be stored in case they were needed later (when the donor might not be available). They discovered that newer techniques for stem cell storage had only recently been approved for use in humans; some of the machines and medical centers using them had yet to be approved by the Food and Drug Administration. Since insurers considered these techniques experimental, no reimbursement was available. Stem cell storage and transplant will cost \$50,000 to 100,000, and it is not yet known if the center at which the transplant would be performed would have an approved stem cell program and machines. To help save money to cover donor costs and other nonreimbursed expenses, a fund was established through Parent to Parent of Vermont, a support organization for families with children with special needs of all types.

To date (September 2000), Thomas has had 61 weeks of chemotherapy, 20 hospitalizations for chemotherapy and blood/platelet transfusion, and more than 50 outpatient clinic chemotherapy and doctors' appointments. He has \$50 to \$300 worth of laboratory tests weekly, and medication has cost more than \$1,300 per dose. An average hospitalization has cost \$7,000 to \$17,500. He has been seen by five oncologists, though the smallest proportion of his bills has been for direct clinical care by physicians and nurses. If Thomas continues to do well, he will be in treatment for a total of 2½ years. If he relapses, the bone marrow transplant may be the only option to save his life.

While in treatment, Thomas has continued to go to school whenever possible and, at age 15, is starting the tenth grade. He has been able to maintain his school schedule by receiving part of his chemotherapy locally.

Ms. Travis expressed appreciation to friends, family, and all of the health professionals providing care to her son.

Key Points

- The emotional and financial cost to the family has been incalculable. To provide the continual care Thomas requires, Ms. Travis has taken a leave of absence from her job, and the family now relies on one income. Countless hours have been spent on research, and hundreds of dollars have been spent on telephone calls, travel, and meals in hospitals.
- In a small State such as Vermont, many specialized laboratory and treatment services are unavailable and have to be arranged in other States. In addition, for teens with rare leukemias such as Thomas', treatment must be individualized, requiring services available only out of state.
- The Traveses conduct research on treatment options by phone, Internet, and through libraries and parent support networks (e.g., Candelights Childhood Cancer Foundation), listservs, and the Leukemia Society.

- Thomas has been helped most by having consistent caregivers who have taken the time to get to know and communicate with him. It has also been important to have clear information about treatment protocols, drugs, and potential problems or side effects. This information has been essential to retaining control over decisionmaking and enabling the family to make informed choices about complicated treatment options. Consideration for Thomas' emotional needs has been very important, and good clinical collaboration among all of the medical services involved has made it easier to cope with the overwhelming nature of treatment.
- Significant problems and sources of stress have included: (1) serious understaffing at the inpatient service and lack of support for doctors and nurses; (2) difficulty in obtaining chemotherapy medications from pharmacies in rural Vermont, especially after hours; and (3) inconsistent drug pricing due to patent changes (e.g., \$959 versus \$444 per dose for the same medication).
- Problems specific to managed care payers included: (1) slow payments to pharmacies, prompting one pharmacy to suggest the Traveses charge thousands of dollars in medication costs to a credit card; (2) repetitious requests for excessive documentation; (3) intrusive phone calls from case managers who behaved as if they were part of the medical team although they had no medical training or expertise; and (4) lack of insurance coverage for marrow donor costs.
- Finding data on high-risk teens was difficult because national databases often incorporate these data into either pediatric or adult statistics.
- Data from international clinical trials do not appear to be used in FDA decisionmaking. Unless the FDA approves new technologies (e.g., stem cell phoresis machines) and treatments, health care providers and families at the local level are impeded from accessing new treatments, however much community support or personal resources they may have.
- Teens desperately need control and a voice in their treatment but are still too young to advocate or care for themselves or make decisions without adult guidance.

Recommendations

- Managed care should be forced to pay bone marrow donor costs at a level comparable to reimbursements for donor costs for other organ transplants.
- Managed care should be forced to provide the services it advertises in a timely, nonarbitrary manner.
- Better regulation and oversight of pharmaceutical and biotechnology companies is needed to ensure safe, ethical treatment and a greater focus on providing treatment rather than generating profit or patenting genetic material.
- Cancer is a public health problem, not a private one. Protecting children's health through regulation and control of known carcinogens is Government's responsibility. Funding is needed for more public health research into cancer clusters, especially where these cross State and national boundaries.
- Teenagers are the most invisible cancer patients and the most at risk. Funding is needed for more research on the biological and developmental differences of teens with cancer. The impact of cancer treatment is long-term, and the need for family support, school intervention, and financial assistance is ongoing.
- Adopted teens with cancer are uniquely at risk, having no knowledge of their genetic or family medical histories. Better medical recordkeeping is essential for all adoption agencies and social services.

MS. KAY PERKINS

Background

Ms. Perkins lives in an area of Vermont known among residents as the Northeast Kingdom. The area is extremely rural, and many of the residents are of limited income.

Ms. Perkins is a member of the boards of a number of community organizations and works with low-income and disabled people in Vermont. In addition, she serves on the State Tobacco Task Force, in part because her husband is a long-term smoker; Ms. Perkins feels her prevention-oriented work through the Task Force is a way of fighting back against the tobacco problem.

Many members of Ms. Perkins' husband's family have had cancer, and Ms. Perkins had lost a sister and uncle to the disease.

Key Points

- Accessing needed health care services is a major problem for rural Vermonters, and treatment delays are common.
- The working poor who receive a cancer diagnosis must deal not only with their own fears and those of their families, but also with the stress of losing time from work and possibly losing their jobs. Meeting daily expenses becomes a serious concern, and the possibility of having to travel to and stay at a distant site to receive treatment creates a significant financial hardship. The ACS has been helpful in advising rural residents and directing them to needed resources, but it does not have the funding or staff to reach and provide needed support services to the population.
- Many rural residents have no insurance or limited insurance that is often refused. As a result, many avoid testing because they are unable to pay for services that would be required in the event of a diagnosis. Many feel that under these circumstances, not knowing one has cancer may be preferable to knowing and being unable to access treatment. Lack of ability to pay for care is part of the fear that a cancer diagnosis means they will be unable to meet daily living expenses and responsibilities.
- Cancer affects not just the patient, but the whole family. Most providers deal only with the patient.
- Discomfort associated with mammography discourages many women from having repeat screenings.

Recommendations

- Many rural residents go to the local social welfare department instead of the doctor. Therefore, it is important to make cancer information available in those offices and in the offices of organizations that provide financial assistance. Television can be a powerful way to get cancer information to rural residents.
- Cancer associations and other community support organizations need more funding and staffing to better reach rural populations.

MS. SHEILA CALLAN

Background

Ms. Callan has lost a friend and many relatives to cancer, including both parents, a brother, an aunt and uncle, and two cousins. Nearly all of the female relatives had breast cancer. Given her family history, Ms.

Callan has been highly vigilant concerning cancer throughout her adult life and has pursued alternative nutritional and healing approaches.

Shortly after a March 1994 auto accident in which she sustained a head injury, Ms. Callan noticed a breast lump. Her doctors believed it resulted from her breast striking the steering wheel during the accident, but Ms. Callan was concerned. Because of the accident, however, Ms. Callan was unable to work for some time and lost her health insurance. Consequently, she did not get a mammogram until October, when she was able to obtain one free of charge through a local Breast Cancer Awareness Month screening program. The mammogram showed an abnormality, and she received a needle biopsy, which was negative. Still concerned, she sought a second biopsy and a sonogram, which revealed a large tumor. She had a lumpectomy in January 1995, followed by radiation therapy.

During this time, Ms. Callan had been living in Rochester, New York. She subsequently moved to Vermont, but returned repeatedly to her doctors in New York because her incision would not heal. She was told it might never heal and that she would have to live with an open wound. Seeking the help of a plastic surgeon, Ms. Callan (whose only insurance at that time was Medicaid) was told she would have to pay \$3,000 to cover the difference between Medicaid reimbursement and the surgeon's customary charge.

In Vermont, Ms. Callan had been volunteering at a local free clinic. She asked to be examined by one of its physicians, who recognized immediately that her cancer had recurred. The clinic arranged all of the needed services to treat her cancer, which was twice as large as her original tumor. Ms. Callan required trans-flap reconstruction because the cancer had spread to her skin and required extensive excision.

Because of allergic reactions to many medications, Ms. Callan was able to undergo only limited chemotherapy. She was referred to the Vermont Cancer Center/Fletcher Allen Health Care, where she was seen by team of cancer care providers. In light of her personal and family history, genetic testing was recommended. Ms. Callan had sought such testing in Rochester, but was denied. Testing revealed a high likelihood that she carried a predisposing mutation for breast and ovarian cancer. Based on the results, another mammogram was performed, and Ms. Callan was again diagnosed with breast cancer. She had a mastectomy, lymph node removal, and oophorectomy.

Ms. Callan noted with appreciation the support she and other women in the community receive from the statewide, grassroots Breast Cancer Network, which offers information and education, research, lymphedema care information, and funds for travel and emergency expenses. In addition, she has been fortunate to be associated with a small and caring community of health care professionals who have been highly supportive.

Key Points

- Comprehensive cancer care is extraordinarily important for patients, both in terms of the types of care available and the assistance many patients need to make informed decisions about their care.
- Waiting for test results is almost as difficult as taking the tests; it would be helpful if patients could be informed of results more quickly.

MS. KAREN KITZMILLER

Background

Ms. Kitzmiller is an 11-year Vermont State legislator from Montpelier. She is also a 5-year survivor of metastatic breast cancer that went undetected despite regular checkups and mammograms.

Over the course of her treatment, she has had to fight her health maintenance organization (HMO) to obtain coverage for recommended treatment regimens, supportive medications (e.g., injections of white blood cells), and oral chemotherapy drugs. For example, the HMO medical director, a general practitioner, opposed the chemotherapy regimen recommended by her oncologist. In addition, she was denied white blood cell injections, which led to a far more expensive, 10-day hospital admission because her white cell count was so low. After a protracted fight, her insurer agreed to pay for oral chemotherapy medication but required that she pay first (approximately \$2,000 a month) and wait for reimbursement. She was only able to do this by carrying the cost on a credit card.

As a legislator, Ms. Kitzmiller has used her personal experience with cancer to help pass laws in Vermont requiring that: (1) patients have the ability to appeal HMO treatment decisions made outside their health plans by a health professional of the same specialty as the prescribing physician; and (2) white blood cell injections be included as part of chemotherapy coverage.

Ms. Kitzmiller had no family history of cancer but noted that as a child in Florida, she was daily exposed to DDT.

Key Points

- Mammography is not infallible; women should not put too much trust in mammography results.
- Health professionals who emphasize unfavorable survival statistics can strip advanced cancer patients of hope and the will to fight their disease.
- When you are fighting for your life, it is virtually more than you can do to also fight the health care system.
- Ms. Kitzmiller noted that she is a middle-class person with some resources, a supportive family, and a strong network of friends. As a State legislator, she has skills, knowledge, and, at least, perceived access to power and the press that many do not have. With all this, however, she had an incredible struggle to get what she needed for her own cancer care. This experience has made her a fierce advocate for people who are less fortunate in any of these respects.
- Insurers are shortsighted in failing to provide coverage for oral chemotherapy drugs and supportive/preventive medications.

Recommendations

- More research is needed on the possible role of pesticide exposure in cancer development.
- States should take the lead of the Federal Government in guaranteeing coverage for the costs of participating in clinical trials. Patients must have full and complete coverage for clinical trials participation. Evidence shows that the cost of clinical trial care is not greater than costs for standard care. Access to trials is essential if cancer care is to be advanced. Few patients can afford to pay out of pocket for clinical trial costs.

RHODE ISLAND

Presenters:

Dr. John Fulton

Ms. Sue Sgambato

Ms. Mary Ann Andries

DR. JOHN FULTON

Background

Rhode Island has been characterized as an “old urban place” because its population density is very high, and the most populous area of this small State, around the head of Narragansett Bay, has been urbanized for 150 years. By 1850, more than half the population lived in urbanized areas, due principally to the textile and other industries in the area. For this reason, it is more appropriate to compare Rhode Island data to those of large cities rather than other States. Like other old urban centers, Rhode Island has an urban cancer profile. The State has high rates of all the smoking-related cancers. Lung, upper digestive tract, kidney, bladder, and pancreatic cancer rates in Rhode Island all exceed national averages. The State has also a high colorectal cancer rate, most likely due to an urban diet low in fruits and vegetables.

Key Points

- The main cancer prevention challenge in Rhode Island is to reduce smoking rates. Unfortunately, the tobacco industry markets actively in the State. The CDC has estimated that Rhode Island needs to spend \$10 million to \$20 million per year to counter the effects of tobacco industry advertising—at least to the extent achieved by States such as Massachusetts and California. Currently, Rhode Island receives \$1 million per year from the CDC and an additional \$2 million from its State legislature for antitobacco efforts. At this funding level, the State is losing the battle against tobacco. Teen smoking rates are higher than ever (nearly 30 percent of high school graduates smoke), although adult smoking rates (currently 23 to 24 percent) are decreasing.
- Although diet is probably linked to the State’s high colorectal cancer rate, research evidence does not exist to support clear dietary recommendations to the public. Moreover, the public is bombarded by conflicting dietary advice through the media, which would complicate the delivery of recommendations even if it were possible to provide evidence-based guidance. Currently, the only ongoing diet-oriented program in Rhode Island is the Five-A-Day program, funded through the State’s prevention block grant.
- The State’s breast cancer screening program has been operating for 13 years, but significant problems still exist; these problems reflect similar problems with cancer screening overall. Breast cancer screening occurs in the offices of primary care providers, and though a woman may receive a referral for a mammogram, the primary care provider has no way of tracking whether she actually received the test until she returns for her next appointment.
- At a personal level, Dr. Fulton noted that both his dentist and optometrist have elaborate reminder systems in place, but that his primary care physician, like most others in the State, has no such tracking system. The State is now discussing the implementation of patient tracking with managed care organizations in Rhode Island that already have the capacity to perform tracking.
- Rhode Island has screening recommendations in its cancer control plan that are consistent with Federal guidelines, but many controversies exist concerning screening. Chief among these is what to recommend in terms of prostate cancer screening. In addition, gastroenterologists in Rhode Island indicate that most primary care physicians who recommend the fecal occult blood test (FOBT) for

colorectal cancer screening do not know how to perform the test. As a result, most of the tests actually performed (a fraction of the number of kits distributed) are useless because of sample contamination. Moreover, there is no quality control in terms of directions given to patients or the handling of samples.

- Sigmoidoscopy is a cottage industry in Rhode Island. It is performed by both gastroenterologists and primary care physicians. No quality control exists for examinations performed by primary care physicians, such as monitoring the cleanliness of the equipment. In addition, the controversy over the relative merits and costs of sigmoidoscopy versus colonoscopy remains unresolved.
- Fragmentation of cancer care is universal and can have clear deleterious effects. In Rhode Island, insurance reimbursement for Phase II, III, and IV clinical trials is mandated by law. Still, less than 5 percent of adult cancer patients are enrolled in clinical trials, and adult cancer care is spread among 12 acute care hospitals in the State. Because patients typically are sent from one doctor to another during and shortly after diagnosis, they often fail to be entered into trials because the time limits between date of diagnosis and trial entry are often exceeded. By contrast, over 75 percent of children with cancer are enrolled in trials, and all are treated at a single facility (Hasbro Hospital), where a concentration of cancer professionals works together to get pediatric patients enrolled in trials as rapidly as possible.
- All patients are underserved for cancer care, but the problem is most severe for the uninsured, Medicaid patients, and those with low incomes. In Rhode Island, these populations receive almost all their care in severely underfunded community health centers. It was discovered that posting an individual in a center to review charts and call women eligible for breast and cervical cancer screening was far more efficient and effective in increasing screening rates than launching a public information campaign.
- The State also discovered that the basic infrastructure of most community-based organizations in Rhode Island is weak. It has been more effective for communicating messages about cancer control to place individuals in the centers than to simply provide funds, which tend to be absorbed into infrastructure maintenance.
- When the Health Department surveyed women as to why they did not get mammograms, respondents indicated that their physicians had not recommended it. The Health Department subsequently worked with primary care providers on this problem, and screening rates improved. Experience has been similar for other screening tests and cancer control measures. For example, when physicians regularly ask their patients who smoke to quit, they can effect a quit rate 3 percent higher than would normally occur in that population.
- Rhode Island desperately needs greater funding for public health efforts in cancer control. NCI database planning funds provided 13 years ago were extremely helpful in that they enabled the State to hire and train people in cancer control and build this infrastructure and capacity at the State level. The State has worked hard to retain these personnel, even when funding specifically for cancer control activities has been unavailable.

Recommendations

- The key to cancer control within the medical system is primary care. Primary care physicians need help to track patients and monitor smoking cessation and cancer screening efforts. In addition, physicians need a system to which they can refer patients for quick entry into clinical trials.
- General funding for administering a cancer control program in every State would be very helpful in enabling health departments to have a greater presence in the community.

MS. SUE SGAMBATO

Background

In 1994, at age 36, Ms. Sgambato found a breast lump during a monthly self-examination. Two years earlier, she had lost her mother to breast cancer, and before that her grandmother, all of her grandmother's sisters, and all of their daughters. All of the female members of her mother's family have died from breast or ovarian cancer.

Over the next 18 months, Ms. Sgambato was diagnosed with infiltrating ductal carcinoma, had a modified radical mastectomy, 6 months of chemotherapy, and a second mastectomy. Eight months later, she had a hysterectomy and oophorectomy.

Ms. Sgambato is a Reach to Recovery volunteer, visiting women newly diagnosed with breast cancer. In 1997, she began the Northern Rhode Island Breast Cancer Education and Support Group, which recently celebrated its third anniversary. She also speaks to women's groups and at high schools about breast health and early detection strategies.

Key Points

- Timely diagnosis is essential. Despite her family history, Ms. Sgambato was told she was too young to have breast cancer and that all premenopausal women had lumpy breasts. Fortunately, she insisted on seeing a surgeon. The surgeon also felt she was too young to worry about breast cancer but performed an excisional biopsy to give her peace of mind. The biopsy was positive for breast cancer; 4 months had passed since she first presented with the breast lump. Younger women are often treated like alarmists when they report symptoms, and are sent home only to find 6 to 12 months later that they indeed have cancer.
- Patients need access to information about their disease and all aspects of care. As a patient, Ms. Sgambato was given little or no printed information and had to search on her own for sources of supplies, breast forms, and other resources. Her surgeon indicated that he would tell her everything she needed to know. She was given no information about physical therapy, social workers, or support groups. As she began to work with other breast cancer patients, she found their experience was frequently similar, and few knew where to look for needed information. Patients who are provided information feel more optimistic about facing treatment and more able to make informed decisions.
- The problems patients may face after cancer treatment are often undertreated by health care providers and misunderstood by employers, family members, and friends. Ms. Sgambato's physicians were of little help with the severe depression, migraines, and hot flashes resulting from her treatment-induced menopause. Moreover, they suggested she should just be glad to be alive. There is little recognition that a survivor's life is never the same as it was before the cancer diagnosis and treatment; it is expected that the survivor will just get on with his or her life and forget about the cancer experience. However, survivors continually worry about recurrence and seek ways to stay healthy. Doctors have little information about the benefit of the many complementary therapies and supplements available.
- Though Rhode Island has many competent, caring medical professionals and excellent medical facilities, it is hampered by territorialism on the part of some physicians and a lack of coordinated cancer care and service delivery. Positive changes have been achieved over the past 6 years, but there is still room for much improvement.

MS. MARY ANN ANDRIES

Background

Ms. Andries has lost eight relatives to cancer, though not all have had the same type. (These include thyroid, stomach, nose/face, colorectal, pancreas, brain, breast, and one of unknown origin). In addition, one family member has survived breast cancer, and others have been diagnosed with benign and precancerous colorectal polyps.

For some years, Ms. Andries' physicians asked only about her family breast cancer history, but her gynecologist, upon learning about her cancer history in general, suggested a sigmoidoscopy. Ms. Andries is the caregiver to two parents in their eighties, and so did not get the test until it was also recommended by the internist who cared for both her mother and herself. Ms. Andries' mother had had benign colon polyps in the past. Though her sigmoidoscopy was negative, the doctor suggested she receive a colonoscopy. The colonoscopy revealed a precancerous adenoma, which was removed. In addition, Ms. Andries' father was diagnosed with a large precancerous polyp that was undetected by either sigmoidoscopy or ultrasound. Mr. Andries had his first colonoscopy at age 60, revealing a precancerous adenoma in the cecum. Father, daughter, and son each had a precancerous adenoma located in the cecum and ascending colon that could be detected only with colonoscopy.

Ms. Andries has become involved in community education about colorectal cancer screening and has also used her personal experiences to urge her friends and relatives to have colonoscopies

Key Points

- Colon cancer is still considered a man's disease by many; therefore, women may not request screening.
- The directions for collecting stool samples for the FOBT are unclear and directions on the packet may vary from those given by the physician's office. The confusion caused by this situation likely contributes to patients' hesitation to do the test.
- Because families are now so mobile, regional cancer statistics may not accurately reflect the cancer profile of a given geographic area.
- Personal experience has convinced Ms. Andries that FOBT and sigmoidoscopy are insufficient for screening many people. Colonoscopies are a must. In addition, some physicians are not recommending colorectal cancer screening, and patients are not being diagnosed until they have advanced cancer. It is also true that some patients ignore symptoms until their disease is advanced. In other cases, patients' cancer is misdiagnosed or diagnosis is delayed until the disease is advanced. These situations occur even among the educated, well-to-do, and well insured. Ms. Andries cited the cases of two female friends who died of cancer in their forties; both were married to physicians.
- Patients are not routinely given pamphlets or other existing information produced by the ACS, American Heart Association, and other organizations. This information could be available in physicians' offices. Many patients are capable of collecting information from the Internet, but it is time-consuming. Television can be a blessing or a curse in terms of getting information to the public. Many of the stories portrayed on television have been beneficial in promoting healthy behaviors (e.g., the story of Katie Couric's husband, who died of colorectal cancer, has raised awareness of the disease); conversely, reports of studies that contradict public health recommendations may cause people to change behaviors that were protective.
- It is imperative that insurance companies pay for screening colonoscopies. As with mammography, colorectal screenings for the un- and underinsured must be addressed.

MASSACHUSETTS

Presenters:

Ms. Patricia Brennan
Ms. Geraldine Malter
Dr. Dennis Derman
Ms. Janet McGrail
Mr. Larry Pizzi

MS. PATRICIA BRENNAN

Background

Ms. Brennan directs the Massachusetts Department of Public Health's Office of Cancer Research, which administers grants in prostate and breast cancer research in the State. The program is aimed at early-career scientists investigating all aspects of these diseases. Inquiries are invited; Ms. Brennan's telephone number is 978-640-1027.

Key Points

- Populations in Massachusetts considered to be underserved for cancer prevention and care include the underinsured, the uninsured, low-income residents, people of color (including African Americans, Latinos, and Portuguese), new immigrant populations (including Haitians, Cambodians, Vietnamese, Russians, and refugees from the Baltic states), rural residents, and gay men and lesbians.
- Barriers to appropriate cancer treatment include language and financial barriers, transportation problems among rural residents, cultural barriers, health care providers' lack of knowledge and training (e.g., in performing colorectal cancer screening), and the perceived barrier of excessive distance from care.
- Two years ago, Massachusetts received CDC funding for a comprehensive cancer control program. At that time, it was one of six States and tribes to receive such funding; one additional State has since been similarly funded. The purpose of the funding is to coordinate cancer control efforts among all State organizations involved in cancer control. Massachusetts has formed a Cancer Control Advisory Committee comprising these organizations. Among other activities, it coordinates and standardizes messages to the public about cancer screening and treatment. Efficiencies have been achieved in that educational materials development and production has been restructured to avoid duplicative efforts.
- The Massachusetts Colorectal Cancer Working Group is part of the cancer control program. It is researching geographic gaps in colorectal screening in the State and has identified several areas with disparate screening rates. It has produced two series of professional and public education materials and run a statewide transit campaign.
- The CDC cancer control funding also supports two studies being conducted through the Massachusetts Cancer Registry: One focuses on stage of diagnosis, the other on standards of treatment for prostate, breast, and colorectal cancer. In conjunction with the State medical society, the State Medicare organization, a major insurer, and the Board of Registration of Medicine, the Cancer Control Advisory Committee is collecting data on breast cancer screenings by geographic area. Following data collection, a letter will be sent to all physicians informing them about screening rates in their areas.
- The State also funds a chronic disease prevention program for underserved populations that produces prevention information materials and trains outreach workers. In addition, Massachusetts has a federally funded breast and cervical cancer screening program that includes an outreach component.

Participating agencies have a minimum number of women whom they must screen; most are exceeding this minimum requirement. A second case-finding activity has recently been funded.

- The Women's Health Training Institute is a State-funded grant to the Boston University School of Medicine to train physicians, radiation technologists, nurse practitioners, and physician assistants in standards of care and cultural competency. The program, which conducts 25 training sessions annually, has been effective in overcoming barriers created by lack of provider sensitivity to issues relevant to various underserved populations. A similar program is being launched for outreach workers in the State.

MS. GERALDINE MALTER

Background

Seventeen years ago, Ms. Malter had surgery to remove a 7-pound retroperitoneal liposarcoma. At the time, she was 38 years old, living in Boston, the mother of two, and the wife of a physician. She asked her oncologist about the availability of a support group, but there was no group for sarcoma patients. She was referred to a psychiatrist, which proved unsatisfactory. It took 6 years for her to find a support group for women with cancers other than breast cancer.

Ms. Malter had four abdominal operations in the year following her diagnosis. She did not realize, nor did anyone tell her, that sarcomas are rare cancers. However, her doctor did tell her that the disease was very likely to recur and that he would not tell her the survival statistics for her disease because they were not meaningful. Ms. Malter recognized her need to become educated about her disease so that she could proactively participate in her treatment and discussions about it.

After she had survived 5 years from diagnosis, her physician relaxed her followup care schedule. Three years later, Ms. Malter was diagnosed with a major recurrence that resulted in surgery in which she lost a kidney, her spleen, and half her colon; she was in intensive care for several weeks. At that point, her physician made it clear that she should seek care from another physician and referred her to a radiation oncologist. She was advised to have radiation therapy to her abdomen and told that if she did not, she could expect to die within a year. Ms. Malter sought a second opinion. She was directed to Massachusetts General Hospital, where she subsequently was a patient for 5 years. Her tumors were recurring rapidly, and she had many more surgeries. Though she was confident in her surgeon's skills, she felt that his insensitive manner was destroying her hope. This physician suggested she go to the M. D. Anderson Cancer Center in Texas, but a friend told her there was a sarcoma clinic at the Dana-Farber Cancer Center in Boston. Ms. Malter has been a patient there for the past 4 years. Her disease continues to recur.

Ms. Malter helped form the Patient and Family Advisory Council at the Dana-Farber Cancer Center, a group of patients and family members who work closely with the administration on issues of patient-doctor communication, sensitivity, and the general environment of the institution for patients. She also started a patient-to-patient newsletter, *Side By Side*, that is published quarterly and distributed at the Dana-Farber Cancer Center and the Brigham and Women's Hospital. The purpose of the newsletter is to help educate patients about their disease, encourage self-advocacy, and provide support.

DR. DENNIS DERMAN

Background

Boston's Lemuel Shattuck Hospital is one of the last public health hospitals in the country. The Boston area formerly was well served by charity hospitals but is now relatively underserved. The Lemuel Shattuck Hospital serves the area's vulnerable populations.

Key Points

- Vulnerable populations not often discussed are the mentally ill, handicapped patients, substance abusers, prisoners, and immigrants. These patients have a considerably different set of impediments to the receipt of proper health care. To greater or lesser degrees, they lack the capability deal with a relatively inflexible system.
- Improving care for these patients requires changes in the existing system that are difficult to achieve, including taking responsibility for the patient beyond the level usually taken by either the institutional or individual provider—even out of the physician’s office. These needs reflect the current lack of integration of health care from the doctor’s office into the community.
- Before medical advances are integrated into routine care, we must first provide an adequate standard of care for all patients. Gene therapy is irrelevant for a patient who cannot get a simple excision of his or her tumor.
- In the case of patients with major mental illnesses, timely delivery of good care is complicated by their inconsistent ability to perceive the threat of the disease and its import and by the fact that many of these patients are self-destructive. Most have already been judged at some level to be incompetent to request or refuse medical treatment. Incompetence, however, is judged variably by psychiatrists, and the nature of the treatment decisions required also varies. At the initial stages of disease, patients are more treatable, but also more mobile, and appear less affected by the disease. At this point, they may have more decisionmaking authority. At later stages of the disease, when they have significant symptoms, they may be judged incompetent to make decisions about their care, and care may be of less utility.
- Substance abusers tend to be unpopular patients; unfortunately, they are extremely difficult patients because of the nature of their disease. By the time most have reached the public hospital, they have few resources or support upon which to draw. These patients badly need support services in the community. The families with which they are involved also need support, and patients are likely to be more cooperative with support provided through the family than through addiction-oriented interventionists, who may be viewed as paternalistic.
- Prisoners are a distinctly unpopular patient group. Unfortunately, this is a burgeoning population. Though frequently suffering from mental illnesses and unable to adequately make decisions about their care, they are to a large extent able to deal with their disease. Living in an extremely inflexible system, they are not arbiters of their own care and cannot advocate for themselves. It is also often necessary to badger people within the system to ensure that patients are brought back for care when they would otherwise be neglected.
- Immigrants, especially illegal immigrants, face barriers related to language and cultural differences when attempting to access health care. Available translation services may be inadequate. The Lemuel Shattuck Hospital reaches out into these communities for translation and outreach services appropriate to these populations.
- The deleterious effect on these vulnerable populations of the lack of application of a consistent, acceptable standard of care far outweighs any benefit derived from new discoveries.

Recommendations

- One way to improve health care for mentally ill cancer patients might be to develop a class of psychiatrists with special expertise in cancer to participate in tumor board discussions or otherwise assist in informed decisionmaking for these patients.
- Greater attention should be paid to improving the standard of care for vulnerable cancer patients, including the mentally ill, substance abusers, prisoners, and immigrants.

MS. JANET McGRAIL

Background

Boston's Crusade Against Cancer is a unique program in which the mayor's office, the Boston Public Health Commission, and the ACS are working together to try to cut cancer rates in half by 2015. Using information about cancer incidence and mortality, access issues, and barriers to care, Boston is working to educate, raise awareness, and provide cancer screening opportunities for residents. Ms. McGrail is involved in creating programs and social marketing efforts to reach the most vulnerable populations.

Key Points

- In Boston, twice as many white women are diagnosed with breast cancer as black women, but black women have twice the mortality rate of white women. The Breast Friends program, an outreach program to women of color, is attempting to address this disparity. Paid outreach workers hold gatherings similar to Tupperware parties in homes, schools, and churches. Women who attend a party receive a followup call offering to book a mammography appointment, provide transportation and daycare, and accompany women to screening. The goal is to remove barriers to screening access.
- To reach uninsured women with mammography, the city of Boston purchased a mobile mammography unit. The van operates 5 days a week and serves women who "fall through the cracks": women in jails, in addiction recovery programs, the homeless, and the uninsured.
- To address transportation barriers, a task force established by the mayor set a goal that 100 percent of Boston's cancer patients would have access to transportation; this goal has been achieved. The city works with 10 hospitals to make sure no patient lacks transportation. The program is administered by the oncology social workers in each hospital. To date, almost 4,000 rides have been provided.
- Boston has also reached its goals for public education. Last fall, 251,000 brochures were mailed to all city households. The culturally competent messages stressed the benefits of good nutrition, exercise, and limited sun exposure and provided cancer screening guidelines. The brochure, available in nine languages, was developed through a collaboration between the ACS, Harvard School of Public Health, and Boston Public Health Commission.
- The Boston Public Health Commission was one of 30 agencies nationwide to receive a CDC Reach 2010 grant to study racial disparities experienced by women seeking breast and cervical cancer screening in the city. The steering committee for the grant identified women to participate in focus groups and conducted a needs assessment based on a survey of attitudes, beliefs, and practices. Community meetings were held monthly, and outreach was conducted at festivals, fairs, parades, and churches. Community women and coalition members were trained in breast and cervical cancer education, antiracism, self-help, coalition development, and grant writing. On October 8, 2000, breast and cervical cancer education will be conducted at various black churches throughout the city. Discussions at the community meetings revealed that women lacked knowledge about early detection, particularly if they had no source of primary care or did not see the same doctor consistently. Other barriers included: fear of pain caused by mammography, hesitation to be screened if no symptoms were present, fatalism about cancer, belief that family and work responsibilities were more pressing than personal health concerns, lack of health insurance, resistance to real and perceived racism of providers, lack of sensitivity to cultural differences, lack of respect if uninsured, hesitation to ask for interpreters or assistance in filling out forms, inconsistent care by multiple providers in whom patients had no trust, and lack of culturally relevant support systems.
- In 2000, Boston's Crusade Against Skin Cancer worked with the city's summer job program to provide information on sun exposure and smoking to 5,500 teenage employees. Information was also

distributed through the Boston Parks and Recreation Department and community center camps. Skin screenings for the elderly were conducted throughout the city.

- The city has tried to capitalize on various established community events and has created “public health moments” and infomercials focusing on breast, prostate, colorectal, and skin cancers. These have been presented at concert series and gatherings of elderly residents and other target populations.
- Millions of lives can be saved by taking what we know to the people; this is best done by coordinating with partners to provide programs and education. The mayor of Boston has shown great leadership in creating a plan, providing resources, and making the plan a reality. He has also shared information about Boston’s efforts with the U.S. Conference of Mayors.
- Research shows that increased cancer education can affect cancer incidence and mortality rates. The challenge is to get all cities and towns to develop and implement cancer control programs.
- Experience has shown that positive results can be achieved by removing economic barriers, creating targeted programs and taking them to the people, following guidelines, providing materials in different languages, employing staff reflective of the target population, and using established mechanisms to deliver messages.

MR. LARRY PIZZI

Background

Four and one-half years ago, Mr. Pizzi lost his 12-year-old son, Tim, to brain cancer. Mr. Pizzi is actively involved in advocacy to promote efforts to find a cure for brain tumors.

Key Points

- There is often conflict in the principles of quality care between wanting care that is medically and scientifically centered and a desire for patient autonomy and empowerment. This tension is not necessarily bad; it can add a dynamism and robustness to care that ensures that all concerned ultimately focus on the well-being of the patient.
- The following principles of quality care are derived from statements of the Cancer Leadership Council, the North American Brain Tumor Coalition, and Mr. Pizzi’s 11 years of involvement in the cancer community, including 7 years as the parent of a cancer patient:
 - The best care is informed care. Cancer patients and their families must have access to complete, accurate, and understandable information concerning their diagnosis, treatment options, and treatment benefits and risks to enable them to be full partners in decisionmaking. The best care plan is a cooperative effort among physician, patient, and family. This issue involves attitude as well as access; some physicians remain hostile to patients who seek information on their own or want to be actively involved in their care.
 - The best care requires the best diagnostics. Early diagnosis is critical to improved outcome; patients with symptoms should not be denied access to state-of-the-art diagnostic tests. Physicians must not be constrained by pressure to reduce costs, and insurance plans should provide physicians with the tools they need to minimize the impact of a disease rather than hamper efforts to detect and treat early. The long-term costs of missed or misdiagnoses must be far greater than the costs of tests designed to accurately detect and diagnose cancer in its early stages.
 - The best care often requires the best referral. If cancer is suspected, the patient should be referred to a cancer specialist for timely confirmation of the diagnosis and initiation of treatment. Some patients are told their tumors are inoperable or untreatable when, in fact, a specialist at a Center of

Excellence could indeed treat their disease. Patients often must fight both health care and insurance systems to secure second opinions from Centers of Excellence. Some physicians provide these consultations for free, but when there is a cost involved, insurance should cover it.

- The best care may be in a high-quality, peer-reviewed clinical trial. Cancer patients should be guaranteed access to clinical trials, since trials often represent the best treatment option. As with information, this is an issue of attitude as well as access. Removing the barriers to clinical trial enrollment is important not only for the treatment of individual patients, but to the research that will eventually lead to a cure. The administration's decision to require Medicare coverage of routine patient care costs of clinical trials should be a model for private insurers.
- The best care is comprehensive care. Quality care includes access to supportive therapies and services, including those to manage pain, nausea, fatigue, and infection, and services to help patients and caregivers cope with emotional and practical concerns. There are more cancer patients and long-term survivors than ever before, and they have continuing needs that must be addressed, including followup care that emphasizes health promotion, disease prevention, and rehabilitative services.
- The best care maintains the highest quality of life. Choice of treatment should be defined not only by survival statistics, but also by quality of life. Sometimes maintaining quality of life requires more and more expensive treatment; in such cases, the insurance plans must cover this care. Conversely, sometimes quality of life is best maintained by less treatment, in which case a caring physician must be willing to step aside.
- The best care may mean no treatment. At some point, it may be best to end treatment, but this does not mean ending care. People with cancer and their caregivers must have access to end-of-life services, psychosocial services, hospice care, and bereavement counseling. This care is essential and may be a necessary and natural component of truly comprehensive care.

Recommendations

- NCI has taken steps to simplify and expand its databases for patients; State and local governments should emulate and expand on these efforts.
- Advocates, the nonprofit community, and patient support organizations should be involved in public policy at all levels; these groups are accustomed to working efficiently and thinking innovatively because they have had to do so to get what they need. These skills could be used to benefit traditional policymaking processes.

DISCUSSION—STATE OF MASSACHUSETTS

Key Points

- Barriers to involving advocates and consumers in policymaking seem to be breaking down. However, achieving such change has required significant effort on the part of advocates. The patient community should be involved whenever a program is established that will affect patients, families, and treatment.
- Available information may not be good information. To address this problem, the Dana-Farber Cancer Center has three staffed resource centers to help patients and families find information and ensure that the information is reliable and accurate. It was noted that while this is a good step, patients frequently find that even information received from the medical community or government may not be good information. Issues remain as to how to help patients assess the quality of information and how to assist those without access to the Internet or a Comprehensive Cancer Center. People need to

be educated on the need to get information from a variety of sources and how to analyze that information.

- Patients can receive vastly different opinions on the best course of care from equally qualified specialists who simply have different viewpoints. For patients with rare cancers, and many others for whom the optimal treatment is unknown, there may be no other recourse after analyzing the data than to go with one's "gut feeling" about the best course of action.
- Patients in Massachusetts who are HMO enrollees can usually access care from specialists who are not part of the plan, but they have to expend a lot of energy to overcome the health plan's resistance to give approval.
- Efforts are underway to pass a Patients' Bill of Rights in Massachusetts.
- Most underserved Vermonters do not have Internet access. Social service agencies, rather than physicians' offices, are where patients are most likely to receive pamphlets and other information. In the Boston area, computers are being placed in community health centers to enable people to seek information on the Internet, and classes teach seniors how to use the computer and Internet.
- In Boston, poor and uninsured women involved in the Breast Friends program who have abnormal mammograms are referred to Boston Medical Center, where the city has arranged for them to receive free care as needed. The process for treating women with stage 1 or 2 cancer tends to be smoother than for those with more advanced disease. The Breast Friends program has patient ambassadors who follow up with screened women and accompany them to diagnostic and other care. The Ambassador program, which was inspired by the Patient Navigator program at Harlem Hospital in New York, has been especially successful with immigrant and non-English-speaking patients. The Massachusetts Department of Health has agreements with all of the Boston hospitals and the ACS so women receiving free treatment can get access to any specialist, treatment, or support service needed. In addition, agencies funded to conduct breast and cervical cancer screening must agree to follow patients through treatment. These arrangements are somewhat unique in the Nation—and even in Boston—since women seen in other health centers or programs do not have the same access to diagnostic and therapeutic services. Dr. Freeman suggested that the system described be documented in detail so that it can be used as a model for other communities.
- In most communities, women screened for breast and cervical cancer through Federally funded programs have a difficult time accessing needed treatment, especially surgical services. The system of charitable care in this country, which never was perfect, is deteriorating due to changes in the health care system. Poor patients have trouble accessing care, even in public hospitals.

MAINE

Presenters:

Ms. Barbara Leonard

Ms. Carol Beagan

Ms. Nadine Bullion

Ms. Rosemarie LaGasse

MS. BARBARA LEONARD

Background

Maine is nearly as large as the five other New England States combined but is more rural than those States. It has the only frontier county east of the Mississippi River, meaning there are fewer than five people per square mile. The concept of *neighborhood* can be difficult for very rural people to understand.

Maine has a school of osteopathic medicine, but no allopathic medical school, Comprehensive Cancer Center, or school of public health. Ms. Leonard noted that the issues cited by Dr. Carney, Ms. Fulton, and Ms. Brennan related to primary prevention, screening, early detection, access to care, vulnerable populations, and provider practices apply equally to Maine.

Each year, 6,800 Maine residents are diagnosed with cancer, and 3,100 people die from the disease. Cancer is responsible for one in four deaths in the State. Maine's cancer death rate did not show the same decline during the 1990s as the national cancer mortality rate, for reasons that remain unclear. However, tobacco use in Maine is extraordinarily high. Breast and prostate cancer incidence rates are lower than the U.S. average, but mortality rates from these disease are essentially equal to U.S. rates. These statistics suggest possible reporting problems, late stage at diagnosis, and/or inadequate treatment. In addition, recent cancer registry data show that from the early 1990s through 1996, cervical cancer deaths increased slightly; the real meaning of this statistic is being investigated, however, since both the population and number of cases are small.

Key Points

The CDC defines comprehensive cancer control as an integrated and coordinated approach to reduce the incidence, mortality, and morbidity of cancer through prevention, early detection, treatment, rehabilitation, and palliation. Maine's health department historically has focused on prevention and early detection, and its breast and cervical health program and Partnership for a Tobacco-Free Maine are similar to programs in other States. However, when the State began its cancer control planning process in April 1999, the need to work with a broader spectrum of partners was recognized to develop and implement a plan that would have an impact on cancer in the State. The draft plan, to be released in January 2001, tries to (1) identify and demonstrate the value of a unified effort of private, public, and consumer groups, (2) incorporate diverse views of people in organizations throughout the State, and (3) base recommendations on science and best practices in cancer prevention, control, and treatment. The objectives in the plan are linked with the Healthy Maine 2010 efforts.

- The cancer control plan has five parts: prevention, early detection, treatment, rehabilitation and survivorship, and palliative and hospice care. The goal for treatment is to ensure that all Maine residents have financial and geographic access to high-quality cancer treatment information and services, including clinical trials that comply with nationally recognized guidelines. Related objectives are to: develop a public awareness campaign to promote and enhance patient and family education; increase access to cancer treatment options regardless of geography or financial resources; increase the number of hospitals participating in the American College of Surgeons Commission on Cancer (COC) program; increase patient participation in clinical trials; and increase the use of National Comprehensive Cancer Network (NCCN) or other nationally recognized guidelines by cancer care organizations and treatment providers in the State.
- Ten hospitals in Maine currently are certified under the COC program, which requires a hospital to provide community education, early detection, treatment, and surveillance. One of the ten hospitals is a Veterans Administration (VA) hospital and does not report to the State cancer registry. Maine has recognized that a second tier of hospitals exists at which a great deal of cancer care is provided. The Maine Hospital Association and the State Bureau of Health are launching an effort to assess the cancer-based activities of all hospitals in the State, with the goal of helping more facilities become COC-certified.
- Cancer is just one microcosm of the entire health care system. Specific interventions and programs may only be “Band-Aids” on a system that is itself critically ill.

Recommendations

- States need more Federal funding to support surveillance efforts such as the Behavioral Risk Factor Surveillance Survey and cancer registries. States also need increased collaboration among Federal agencies, as described by Dr. Kerner, and better dissemination of best practices that can be implemented in the real world. Mechanisms are needed to identify and describe effective, science-based interventions in place at the local level and to make this information available from a central, national resource.
- Funding and support are needed for comprehensive cancer control planning and implementation, with funding available for use at the State and community levels.

MS. CAROL BEAGAN

Background

In December 1987, Ms. Beagan discovered a 5-centimeter lump in her breast. She had had regular mammograms—most recently, just 8 to 10 months prior to discovering the lump. She immediately had a mammogram and ultrasound, and a biopsy was recommended. After waiting 5 days for the biopsy results, she was told to come in immediately for surgery, as she had a rare, fast growing cancer. Six weeks earlier, her sister had been diagnosed with breast cancer, but there was no other family history of the disease. Despite her son's advice, she declined to seek a second opinion and underwent a mastectomy. Because her lymph nodes were negative, Ms. Beagan believed she was then disease-free. Soon afterward, however, she had significant pain and swelling in her arm; her surgeon told her that 20 percent of women who have mastectomies have lifelong arm problems and that she would have to get used to it.

At this point, Ms. Beagan sought care at the Dana-Farber Cancer Center in Boston. Her physician there determined that she had not had breast cancer at all, but spindle-cell sarcoma in her breast. She had not needed a mastectomy at all. In addition, due to her extensive surgery and resultant scarring, Ms. Beagan had lost the use of her arm. Physical therapy and plastic surgery were required to restore arm function and relieve her pain.

Ms. Beagan later learned that the surgeon who performed her mastectomy had never had a patient with spindle-cell sarcoma, had not consulted with the hospital's oncologist about her case, and had previously been reprimanded and suspended for other medical errors. She expressed anger that such information is not available to patients.

As a result of her experiences, both Ms. Beagan and her husband have become involved in a number of ACS-sponsored patient support activities. She is also involved with activities of the Maine Breast Cancer Coalition, including direct advocacy, assisting with a resource guide distributed at no cost to women in the State, and operating a toll-free help line for Maine women. In addition, the Coalition has established a fund to pay for care for uninsured, underinsured, and poor women; the fund was initiated by the donation of a local swimmer who raised more than \$10,000 by swimming nonstop 32 miles across Moosehead Lake. The fund, which has paid bills for more than 20 women, has been replenished by other donors and will also be replenished by a second cross-lake swim by the same individual. Though a small effort compared with community need, to date, no woman who has asked for assistance has been turned away.

MS. NADINE BULLION

Background

Ms. Bullion is Manager of Support Services, CancerCare of Maine. As a social worker, she has since 1981 worked with adults, children, and teens with cancer.

Key Points

- Prevention is critical; early detection is key; access to care is not equitable; quick access to diagnostic services is essential; waits to be seen, to hear results, and to start care are excruciating and dangerous. Hope is fundamental; information is the beginning; partnership and care will lead to success in caring; quality, state-of-the-art treatment that is sensitive, personal, and supportive of family is vital; being able to return to all aspects of a full life is sustaining; and worry never ends. When care cannot bring cure, comfort in all dimensions is a right.
- Access to care and the quality of care a person receives are a matter of money. The uninsured and underinsured have little or no access to primary care and early detection services. They delay and often do not receive needed care. Individuals with insurance must face costs not covered and obstructive case management by insurers. In some cases, uninsured costs of care lead to bankruptcy.
- The influence of managed care in Maine is growing. In addition, proposed Ambulatory Payment Classifications (APCs) will make it difficult to provide newer, more expensive therapies; the cost will be human lives.
- Reimbursement for oncology drugs cannot be cut to the point that research and development are no longer profitable. Inadequate reimbursement to physician offices for the cost of acquiring chemotherapy drugs threatens to destroy physician-based oncology, especially in a rural State like Maine.
- Reimbursement for telemedicine consultations is essential to bring oncology expertise to rural areas.
- The changing financial picture of health care in Maine is affecting the ability to recruit and retain qualified primary care providers, specialists, pharmacists, and nurses. Supportive services have been among the first services to be cut at a number of regional hospitals.
- Fear and avoidance are major factors preventing people from getting the best available cancer care. Though attitudes about cancer have changed somewhat in the past 20 years, misconceptions about prognosis and treatment remain. Many people still do not have access to primary care and, therefore, screening and preventive services. Many also lack resources, education, and information about prevention and the causes of cancer. Other barriers to appropriate care include lack of insurance, unwillingness to ask for assistance if unable to pay for care or underinsured, transportation problems (including minimal public transportation, lack of reliable car, physical ability of older residents to drive long distances or see well at night), difficulties associated with traveling long distances for care (e.g., housing needs away from home, child and farm responsibilities), and resistance to leaving one's hometown.
- Gender is also a barrier; women may have a more difficult time seeking care, being heard, and being accepted as equal partners in the care process.
- Cultural issues can complicate care; for example, Hispanic women find it difficult to be cared for by a male practitioner, since their culture dictates that a woman never expose her body to a man other than her husband. Maine has also a large Native American population whose traditional patterns of care often result in late diagnosis. The northern part of Maine has a French-speaking population that remains outside the mainstream health care system. Migrant workers in the State are often

unidentified. Generally, people from Maine are by nature stoic, which may cause them to resist recognizing health problems.

Recommendations

- More money is needed for screening programs and community education.
- Medicare reimbursement must not be modified in ways that will jeopardize the financial ability of small and intermediate-sized hospitals to provide cancer care. APCs have the potential to make oncology care feasible only in large hospital centers. Proposed changes will compromise both access and quality.
- Policies are needed to create real and lasting incentives to health care providers and consumers to provide and seek preventive care.

MS. ROSEMARIE LaGASSE

Background

The Maine Breast and Cervical Health Program, funded by the CDC, serves many vulnerable, underserved, and underinsured women in the Bangor area. Caring Connections, a program of the YWCA Bangor-Brewer and the Eastern Maine Medical Center, assists women by breaking down barriers to breast and cervical cancer screening, supplying transportation, providing adult and child daycare, assisting with the application process, educating about screening and early detection, and providing volunteers to accompany women to appointments.

Caring Connections provides additional diagnostic and screening services when necessary, and the Eastern Maine Medical Center covers all its own treatment costs for Caring Connections participants through its Eastern Maine Charities program.

About 80,000 Maine women live below 200 percent of the poverty level.

Key Points

- The Maine Breast and Cervical Cancer program is able to serve few women in their forties. Women in their forties who are underinsured or uninsured often fall through the cracks in the health care system. The ACS and American Medical Association recommend annual mammograms beginning at age 40. Many insurance plans cover mammograms only every 2 or 3 years for women aged 40 to 49. Women with breast cancer aged 34 to 45 have a higher mortality from the disease than do women aged 50 and older. Because of higher incidence rates at older ages, however, breast cancer is still considered an older woman's disease. Many physicians do not think to order diagnostic tests on women in their twenties and thirties. Caring Connections tries to address these issues through its Bridging The Gap program, funded through the Maine affiliate of the Susan G. Komen Breast Cancer Foundation. The program provides breast screening to asymptomatic women aged 40 to 49, and screening and diagnosis to women aged 30 to 39 who either have symptoms or a first-degree relative with breast cancer. Though it is able to serve only 20 to 25 women per year due to funding limitations, cases of cancer have been identified in both these populations through this program.
- Maine is a large State, and patients can have difficulty locating support services. Caring Connections oversees 11 ENCORE^{plus} breast cancer support groups in 9 communities located in 7 counties. These support services are needed in every county for patients, families, partners, and children. Few hospitals or agencies are able to provide these ancillary services.

- Though they have a positive impact in the community, the Caring Connections and Bridging The Gap programs cannot meet the needs of all Maine women who need this kind of assistance, nor can they help their families, partners, and children.

Recommendations

- Congress should pass the Breast and Cervical Cancer Treatment Act, which would give States the option of providing Medicaid coverage for treatment of women with breast and cervical cancer.
- Women with breast and cervical cancer and their families, partners, and children should have support services available.
- Additional research is needed on the links between environmental factors and breast cancer.
- Legislation is needed to keep insurers from discriminating based on genetic information.
- Greater support for clinical trials is needed, and people need to be educated about their value and how to access and participate in them.

DISCUSSION—STATE OF MAINE

Key Points

- The Maine Medical Center has an initiative underway to share NCCN guidelines with primary care physicians in the State. The goal is to help physicians better understand what is important in cancer screening and diagnosis so that they have the information necessary to help patients access needed care. A similar initiative is underway to train physicians about end-of-life care.
- Pursuant to the Maine Comprehensive Cancer Control Plan, a consortium has been established for clinical office systems improvement that includes the professional review organization (PRO), hospitals, and primary care providers. Among its objectives is to help primary care providers track patients through the system. Some concern exists that system changes could result in a loss of rural providers at crucial rural access hospitals, particularly in the northern half of the State.
- Though Maine lacks the number of academic institutions found in other New England States, public health professionals in Maine try to apply best practices and develop programs at the community level. However, they usually do not have the time to document, publish, and present their activities at national meetings—the usual route for disseminating research results and information on program successes. It would be helpful to create a mechanism or infrastructure that would make it easier for professionals in the field to contribute to the body of knowledge on cancer control.
- Providing care in rural areas is both labor-intensive and time-consuming; a single home visit may require 4 to 5 hours of a staff person’s time. Patients routinely drive up to 4 hours, one way, to receive treatment in rural Maine. Methods must be found to shrink these distances by getting providers out into the communities, but even the existing clinic system is being jeopardized by shifting health care dynamics. It is also crucial that the providers who serve rural areas have the expertise to adequately identify, understand, and treat complex cases. A provider network is needed that will enable quality care to reach rural communities.
- Resource allocation issues are being studied at the State level to try to identify solutions to Maine’s health care shortcomings. Discussions about reallocating resources quickly become political, but it is hoped that workable solutions will be implemented through the Comprehensive Cancer Control effort.
- States should not have to cobble together “Band-Aid” programs to fill the gaps in service left by incomplete Federal funding for specific disease problems (e.g., the need to piece together treatment

funding for women whose breast or cervical cancer is detected through the Federally funded screening program).

- Volunteer efforts to raise money and limited foundation grants awarded to pay for the cancer treatment costs of the indigent and underserved are admirable, but are seldom able to meet all the community's needs. Maintenance of local programs is challenged by the need to secure new funding each year.

CLOSING REMARKS, DAY 1
DR. HAROLD FREEMAN

Dr. Freeman highlighted the day's testimony and thanked all of the speakers for their contributions to the Panel's understanding of cancer information and treatment issues in the region.

TOWN MEETING SEPTEMBER 14, 2000

In addition to the scheduled testimony held on September 14 and 15, 2000, the President's Cancer Panel held a Town Meeting to solicit input from the public on issues and problems related to obtaining cancer information and care. The public was invited to attend the Town Meeting to raise questions and share personal experiences, and the meeting was broadcast live on Vermont Public Radio (VPR), enabling individuals in the listening area to participate and speak directly to the Panel via telephone. Questions or comments also could be submitted by facsimile or e-mail. Dr. Harold Freeman, Chair, and Ms. Frances Visco represented the Panel. Dr. David Yandell, representing the Vermont Cancer Center, spoke to local health system issues. The meeting was moderated by Steve Zind of VPR.

OPENING REMARKS

Dr. Freeman, Ms. Visco, and Dr. Yandell welcomed meeting participants and described the purpose of the Town Meeting: to hear directly from people in the New England area about problems they experience in accessing cancer information and care.

Key Points

DIANA HICKS—WILLISTON, VERMONT

- Ms. Hicks was fortunate to have both insurance and a primary care physician who strongly encouraged her to get a mammogram while she was in her early forties. The mammogram detected early breast cancer; 3 years later, Ms. Hicks remains cancer-free and is a competitive bicycle racer. She encouraged people to remember that the Vermont Cancer Center is a not-for-profit hospital at which people can receive treatment regardless of ability to pay.

LARRY FORTIER—WINOOSKI, VERMONT

- Mr. Fortier is a 5-year survivor of extensive skin cancer that required major reconstructive facial surgery. He believes he was fortunate to receive his care at the Vermont Cancer Center at a time when both new medications and surgical techniques were available.

DR. YANDELL

- Access to care in rural New England is difficult for several reasons. People live long distances from the nearest hospital or physician, and weather conditions at certain times of the year make travel particularly difficult. These distances and conditions also affect home-care nurses who attempt to travel to see patients in remote communities. Vermont also suffers from a nursing shortage, including hospice and respite-care nurses, so providers who are available have heavy workloads. In addition, access to clinical trials is limited in Vermont. The State has only one academic medical center, although the Dartmouth-Hitchcock Medical Center in New Hampshire provides state-of-the-art care to residents of the eastern part of Vermont.

MS. VISCO

- Consumers need to educate themselves about the language and concepts of science to help ensure that they get appropriate care. In addition to the underserved who often receive too few services, a segment of the population may be referred to as the *overserved*; these people may be overtreated

because they have the resources to access care of all types. Both may receive inappropriate care. As advocates, people need to understand the evidence that underlies the treatment recommendations they receive, as well as the most recent discoveries, their impact on care, and potential barriers to the delivery of the right care for each individual.

Cancer care, often an ongoing process, is simply not available to many in this country because they are uninsured or underinsured and cannot afford the out-of-pocket costs of treatment. It is a national disgrace that tens of thousands in this Nation cannot afford to get cancer treatment when they need it.

DR. FREEMAN

- Eighteen percent of the U.S. population (44 million people) has no health insurance. It is estimated that a larger number, as many as 60 million, have insurance insufficient to treat a complex disease. Yet another group of people may get inappropriate treatment, as suggested by Ms. Visco. Many of the uninsured seek care in emergency rooms and are referred to a clinic with the recommendation to first seek Medicaid coverage. Lack of insurance, poverty, and lack of education together comprise a significant set of barriers that keep people from accessing the health care system for cancer treatment and other types of care.

MS. VISCO

- Since the effort to pass universal health care legislation failed in the early 1990s, advocates and others have adopted an incremental approach to improve access to clinical trials and other aspects of cancer care specific to particular cancers. The current effort of the President's Cancer Panel is to identify common barriers to care and make public policy recommendations that will address as many of the barriers as possible.

DR. FREEMAN

- Political and policy changes occur when the public demands change. The Panel can be instrumental in raising awareness of issues and recommending change to address issues, but the voice of the public is what the President and Congress hear best.

KEVIN HOLIVER—UNIVERSITY OF VERMONT MEDICAL SCHOOL

- Mr. Holiver, a colon cancer survivor, is completing his clinical training in oncology; he would like to practice in a rural setting but the need to repay his educational debts (approximately \$200,000) will likely prevent him from doing so. Ms. Visco indicated that presently, there is no legislation in place to forgive the medical debt of individuals who choose to practice in underserved areas. Such legislation existed several years ago, offering debt relief to individuals who agreed to pursue AIDS research. In the current political climate, a medical training debt relief program is unlikely unless the public identifies the need and pushes for appropriate legislation.

ROY NEWER, BURLINGTON, VERMONT

- A prostate cancer survivor, Mr. Newer noted the uncertainty men with this disease face in trying to choose the best treatment option. More research is needed to make it possible to identify which prostate cancers require aggressive treatment, with its attendant side effects, and which do not. This issue is intensifying as the population ages. Ms. Visco indicated that the issue of identifying useful biomarkers and determining which cancers require treatment is a new and difficult challenge common to the treatment of many cancers. Lacking this knowledge, we now treat all early cancers as if they will become life-threatening.

DR. FREEMAN

- Medical research funding should be increased significantly, and the political will exists to allocate these funds. There is a tendency to compare funding for one cancer with funding for another cancer, putting organ-specific research in competition for resources. History has shown that discoveries important to the understanding or treatment of a specific cancer frequently comes from basic biological research or research pertaining to another cancer type.

DEANNA SMITH—SOUTH BURLINGTON, VERMONT

- Ms. Smith, aged 81, is an 11-year survivor of colon cancer. At the time of her diagnosis, she was treated with fluorouracil (5-FU), the standard treatment for the disease. She had a severe adverse reaction to the drug and was told by her doctor that no other treatment was possible. At the urging of her son, Ms. Smith sought treatment in Washington, DC, where she was given 5-FU slowly, over a 3-hour period; she was able to tolerate the drug when it was administered in this manner, and she has since been cancer-free.

CARL BAYER—ST. JOHNSBURY, VERMONT

- Mr. Bayer expressed concern that insufficient attention is being paid to environmental causes of cancer. Dr. Freeman replied that it is believed that a third of cancers are related to tobacco use and another third to diet; thus, two-thirds of cancers may be avoidable. Less evidence exists about other environmental influences and their relationship to cancer; more research in these areas is needed. Ms. Visco added that several bills are now pending before Congress to increase Federal research investment in cancer prevention, and there is more research interest in environmental causes of cancer. This shift in attention has occurred only because the public has become vocal about its concerns in this area; the public will have to continue to demand attention to these environmental cancer issues to ensure that the necessary research is conducted and answers to these questions are found.

DR. FREEMAN

- Public education is crucial to cancer prevention. Educating teenagers about the risks of tobacco use is perhaps the single most important message we can convey; 90 percent of habitual smokers start as teenagers. We need to deal with the teenage smoking issue more aggressively.

DR. YANDELL

- Skin cancers are extremely common and highly preventable. It is especially important to protect children's skin, since the damage that leads to skin cancers at older ages typically occurs in youth.

LARRY PIZZI—BOSTON, MASSACHUSETTS

- Mr. Pizzi questioned whether the academic medical centers reward basic research at the expense of translational research that moves basic discoveries to clinical application. Dr. Freeman agreed that a problem exists, but he indicated that support for translational research has grown markedly in the past decade. He suggested that population-based cancer control research has received the least research attention to date; this research is essential to learn how best to reach population groups in the neighborhoods of the Nation where people live with or die from cancer. He reiterated, however, the importance of conducting adequate levels of research across the research spectrum.

ROD McGIVER—MIDDLEBURY, VERMONT

- Mr. McGiver was diagnosed with stage 4 Hodgkin's disease 6½ years ago. He received chemotherapy for 2 years and was scheduled to receive a bone marrow transplant; however, his blood counts were too low to tolerate the treatment, and his disease was progressing rapidly. He was able to secure treatment with an immune therapy developed and manufactured in Germany. The drug, which has been in tests in the United States for 14 years, has had limited success but caused Mr. McGiver's tumor to disappear within 3 to 4 months. He expressed concern that people with cancer generally cannot access drugs such as these and that smaller drug development companies conduct clinical trials and seek drug approval in other countries because of the duration and expense associated with the Food and Drug Administration (FDA) approval process. Dr. Freeman indicated that while it should be possible to streamline the FDA process, the process is designed to protect the American public from drugs that are ineffective or harmful. The experience of a single individual with a particular drug is not sufficient to conclude that we should quickly adopt the use of drugs not proven safe and effective by our systems.

WILFRED LaFLAMME—RICHMOND, VERMONT

- Mr. LaFlamme was diagnosed with colon cancer 4 years ago, and 4 of 19 lymph nodes were positive. After treatment, he had 3 years of apparent remission. He learned from a Mayo Clinic newsletter that colon cancer survivors should receive periodic chest x-rays, since the disease tends to recur in the lungs or liver. Mr. LaFlamme's requested a chest x-ray although his physicians had never suggested he receive this test. The chest x-ray revealed an abnormality in the left lung, and a biopsy was performed. He was initially told he had a new primary lung cancer; the next day he was told it was a recurrence of colon cancer. Subsequent MRI and PET scans confirmed the lung as the only site of recurrence. Mr. LaFlamme believes his case illustrates the need for better quality control in cancer care.

MS. VISCO

- Mr. LaFlamme describes a barrier to quality care that is not often discussed—lack of information in the medical community about the appropriate intervention in a particular medical situation. Too many members of the public believe that if they just get to a doctor and do as they are instructed, they will receive quality care. In fact, each person needs to research his or her disease and proactively seek the care that has been shown to be important.

DR. YANDELL

- People need to understand that every cancer is different and that cancer is a complex disease, particularly when it recurs. It is not unusual for a person to develop a second primary cancer while being treated for the first cancer, or thereafter. Moreover, not all breast cancers, for example, are the same, even at the same stage of disease. This variability causes different individuals to respond quite differently to the same drug regimen.

The health care system in the United States is different from the systems that exist in many other countries. For example, in some Scandinavian countries, particular cancer types are treated at only one facility in the country; anyone with that disease then goes to that hospital. This arrangement may or may not be better than the U.S. system, in which specific cancers may be treated at many facilities, but it does have the advantage of minimizing the amount of information that must be communicated to all cancer care providers about a given disease.

LORRAINE GOOD—BURLINGTON, VERMONT

- Ms. Good, age 52, was diagnosed with breast cancer 5 years ago. She has had successive rounds of treatment for recurrent disease throughout this period and is now fighting metastatic breast cancer. She observed that the United States seems to have little rehabilitative treatment available for survivors; she has found such programs in Canada and Holland, where she lived during part of her cancer treatment.

MS. VISCO

- The many physical, psychological, and social issues of cancer survivors have been largely ignored until very recently. These issues have now become part of the public debate because patient advocates raised their voices and demanded that these issues be acknowledged. NCI now has an Office of Cancer Survivorship, and many groups have been formed around the country to address these issues.

THOMAS DAVIS, M.D., NORWICH, NEW HAMPSHIRE

- Several years ago, the Dartmouth-Hitchcock Cancer Center, in collaboration with the University of Vermont, conducted a study that found that lung cancer patients in New Hampshire and Vermont who lived more than 75 miles from a cancer center had only a 15 percent chance of being referred to that cancer center for treatment. Based on these findings, Dartmouth-Hitchcock has been sending its physicians out into community hospitals to run clinics and administer treatment to patients locally. This arrangement has enabled the cancer center to bring clinical trials out into the community. The cancer center also educates local physicians and nurses on state-of-the-art cancer care, including screening, treatment, treatment for side effects, and palliative care. More Federal support is needed for this type of care, as it is more expensive than providing treatment at the cancer center. Dr. Yandell agreed that more support for such community care is needed, but also observed that there are some providers and services and some kinds of equipment that cannot reasonably be taken into the community setting. Dr. Freeman noted that a similar partnership has been established in New York City between Harlem Hospital and the Memorial Sloan-Kettering Cancer Center. Ms. Visco indicated that such models are gaining support at the Federal level; for example, the Department of Defense breast cancer research program has funded innovative infrastructure grants to help bring clinical trials to the community setting.

MICHELINA WASSONG—TOWNSEND, VERMONT

- Four years ago, Ms. Wassong's 15-year-old daughter was diagnosed with Hodgkin's disease. The family has insurance through his employment. In the course of his daughter's treatment, she struggled continually with the insurer, which reimbursed claims inconsistently for the same services and required that many claims be resubmitted multiple times. In addition, the family was not given adequate information by the medical providers as to possible drug reactions, and the meaning of various blood counts and other tests. As a full time employee, and without access to the Internet, she has found it impossible to do the research that would help her better understand her daughter's disease. She believes a support group would have been of help to her and would still like to participate in a group to enable her to assist parents of other newly diagnosed children. Ms. Wassong also noted that her daughter, now aged 20, will soon graduate from college and will no longer be covered on her health insurance; she is concerned about her daughter's future insurability.

MS. VISCO

- The questions raised by Ms. Wassong are political issues that would be addressed by a strong Patient's Bill of Rights and universal access to health care.

SHARON (AUDIENCE)

- This speaker used marijuana to control chemotherapy-related nausea experienced during her breast cancer treatment. Her 82-year-old father, a recently deceased prostate cancer patient, also used marijuana in the last months of his life and found it more effective than morphine in relieving pain from bone metastases. Responding from a personal viewpoint, Ms. Visco suggested that laws regarding the use of marijuana for medical purposes should be changed to reflect the scientific data that support the use of this treatment; Dr. Yandell concurred. Dr. Freeman noted the resistance of some health care providers to prescribing narcotics because of concerns about addiction; he believes this concern is unfounded in the case of people suffering pain from a lethal disease.

UNIDENTIFIED CALLER—CENTRAL VERMONT

- Americans' consumption of dairy products has increased dramatically over the past 30 years. A powerful growth hormone, IGF-1, is a component of the recombinant bovine growth hormone given to dairy cattle in the United States. IGF-1 is also consistently detected in breast, lung, prostate, and colon cancers. The recombinant bovine growth hormone was developed by Monsanto; the company has tried to avoid disclosing that the laboratory animals given the growth hormone died from cancer. Ms. Visco indicated that this issue is currently being studied.

MS. VISCO

- The lack of a Federal program to provide payment for treatment services for uninsured women whose breast or cervical cancer is detected through Federal screening programs is a huge gap in Federal health policy. A bill is pending before Congress to remedy this situation. The bill has broad support, but has not come to the Senate floor for a vote. The public needs to express its support for this measure.

DR. FREEMAN

- Short of enacting universal health care, treatment services should not be denied anyone who is diagnosed with cancer of any kind. This should be the minimum a humanitarian society should offer; the public will need to demand this care in order to create the political will to make it a reality.

BOB MILIMEAD (AUDIENCE)

- Mr. Milimead recounted the case of a brain cancer survivor whose surgery left him with multiple daily seizures that could not be controlled by medication. Subsequent surgery to correct the seizure disorder was unsuccessful and, moreover, destroyed his sight. Afterward, he tried using marijuana, which controlled the seizures completely. The public needs to speak out to change the existing prohibitions on medical marijuana use.

TIM SHERMAN—WESTPORT, NEW YORK

- The spring-fed water system in Mr. Sherman's town has recently been chlorinated. He expressed concern about carcinogenic THNs that are formed by the interaction of chlorine and organic matter in water.

DR. YANDELL

- Additives used to purify either the food or water supply are often viewed as bad things, yet in the last 100 years, substances used to purify the food supply have been responsible for significant declines in

certain cancers. For example, the incidence of stomach cancer in the United States has declined, almost certainly due to the lack of fungal contaminants in grain, the availability of refrigeration, and other measures that have resulted in a cleaner food supply. It is difficult to determine the relationship of contaminants, purifying agents, and pesticides to cancer because most cancers take many years to develop, and it is extremely difficult to get data on exposures that may have occurred 30 to 40 years ago and perform the necessary reverse research. In addition, cancer is relatively rare; small groups of people who have particularly high occupational exposures have been studied, albeit with difficulty, and tracking populations with more limited exposures is even more difficult. From a public health perspective, many of the compounds added to our food and water have been beneficial, reducing disease—including cancer—and saving lives.

DR. YANDELL

- In Vermont and other States, telemedicine is being used to bring state-of-the-art care to rural populations. This interactive video technology enables a physician to interview and treat a patient from a distance, review x-ray and other test results, and guide both emergency and chronic disease care. The technology has the potential to bring certain types of clinical trials, such as behavioral and quality of life studies, to rural residents. Other types of studies, such as those involving experimental drugs, are less suitable for telemedicine applications.

JIM WALLACE, M.D.—BENNINGTON, VERMONT

- The Green Mountain Oncology Group, a community clinical oncology group funded by NCI since 1983, conducts clinical trials in four community hospitals in Vermont: Southwestern Vermont Medical Center, Rutland Regional Medical Center, Central Vermont Medical Center, and Mt. Ascutney Hospital. The program makes new treatments available to patients in or near their homes, promotes prevention specific to breast and prostate cancer, and improves the level of care for the many patients who are not eligible for or do not wish to participate in clinical trials.

ADA SILVERSTEIN, MARSHFIELD, VERMONT

- Ms. Silverstein is a breast cancer survivor, as is her mother. Her grandmother and older sister died from the disease. Ms. Silverstein noted that her sister used alternative therapies during her illness in place of mainstream care. She believes her sister, like many other cancer patients in similarly desperate situations, was led astray by practitioners of these alternative therapies. Dr. Freeman indicated his view that patients should know about and have access to complementary therapies that may be used in addition to standard care; however, those who choose alternative treatments in place of standard care may do themselves grave harm.

DIANNE KIMBALL—VERMONT

- Ms. Kimball's husband, a nonsmoker who maintained a healthy lifestyle, died in 1999 from metastatic lung cancer. He was treated both at the Dartmouth-Hitchcock Cancer Center and in the rural area in which he lived. Ms. Kimball wondered if there is a particularly high incidence of cancer in Vermont. Dr. Yandell indicated that recent data from the Vermont Cancer Registry suggest that Lamoille, Franklin, and Orleans counties have statistically higher male lung cancer incidence rates than the rest of the State; certain other counties have an unusually high incidence of colon cancer among females. He also noted that there is much still to be learned about lung cancers that occur in nonsmokers.

WENDY CARLSON, ST. JOHNSBURY, VERMONT

- The media and health care professionals need to make it clear that breast cancer can happen to anyone; one need not have a family history of the disease. Treatment-related fatigue is a significant problem for cancer patients/survivors. There is a need for student community service programs, especially in rural areas, to help patients with day-to-day tasks such as errands and lawn work.

DR. FREEMAN

- Certain populations in America tend to have late diagnoses of cancer. The critical determinant underlying this situation is poverty. About 35 million Americans live in poverty; these people have poor living conditions, less information, are more likely to engage in risk-promoting lifestyles, and have less access to preventive health care. They ultimately enter the medical system via emergency room, but cancer is a disease that must be diagnosed early to be cured. Late diagnosis means a higher cancer death rate. Among racial/ethnic groups, African Americans have the highest cancer death rate in the country, and the driving factor in black/white differences in cancer outcomes seems to be poverty. Research has shown that when black and white Americans are treated for cancer at the same stage of disease with the same treatment, the results are the same. We are challenged in this country not to consider poverty a hopeless condition. We may not be able to prevent people from being poor, but we can do things to improve the conditions poverty causes. Education and access to preventive health care, regardless of ability to pay, are crucial needs

JOYCE NEWTON—FAYSTON, VERMONT

- Ovarian cancer symptoms are so subtle that they are often overlooked or misdiagnosed; as a result, most women are diagnosed at later stages of the disease, when the chance of surviving 5 years is only 20 percent. With early detection, 5-year survival increases to 93 percent. Both women and health care professionals are often unaware that menstrual problems, cramping, or indigestion may be ovarian cancer symptoms. Women need to know that the cause of such symptoms must be determined if they are feeling ill and physicians need to listen to women and take their symptoms seriously. In addition, many women erroneously believe that Pap smears can diagnose ovarian cancer.

DR. FREEMAN

- Doctors do need to be alert to early and subtle abdominal and pelvic symptoms in women; however, the real failure in ovarian cancer detection stems from the lack of a reliable marker test. Some such tests exist, but they are not sufficiently reliable. The ovary is a difficult organ to palpate, especially in obese women, and symptoms often do not occur until the disease is advanced. For these reasons, an accurate blood test for ovarian cancer is urgently needed.
- The current budget of the NCI is nearly \$3.5 billion; including research funds from other Government sources, total Federal research funding may approach \$5 billion. An equal or greater amount is spent in the private sector. Very little if any of this money is spent on educating youth about health-promoting lifestyles. Our lifestyles, cultures, diets, and other behavior patterns are learned quite early in life. Programs targeting kindergarten and older children are needed to help promote healthy diets and discourage smoking.

PAT RAYMOND—BENNINGTON, VERMONT

- Both of Ms. Raymond's sons have had cancer; her younger son died of a brain tumor, the older son survived his disease. In addition, Ms. Raymond's father and her two sisters all died from lung cancer. A third sister has survived two cancers.

DR. YANDELL

- People should tell their doctors if there have been multiple cases of cancer, particularly of a specific type of cancer, in their families. Cancer that occurs at an unusually early age (e.g., breast cancer in a 30-year-old woman) may be a warning sign of hereditary cancer. People at high risk for cancer because of family predisposition can be monitored closely or may be treated differently from people with cancers that do not appear to have a hereditary link.

JILL TURULE

- Ms. Turule is a 25-year survivor of breast cancer; half of the women in the last three generations of her family have died from the disease. Researchers seem only to follow women for 10 years after treatment; this fact sends survivors a message of low expectation. Ms. Visco noted that this is another area in which advocates' voices have begun to change traditional treatment; she noted that it is extremely expensive to follow patients for so many years after treatment on clinical trials, but it is necessary to do so.

DAY 2

REMARKS—MR. BERTRAM YAFFE—CHAIR, NECON; PRESIDENT, YAFFE FOUNDATION

Background

The New England Coalition for Health Promotion and Disease Prevention (NECON) is a coalition of New England State health departments, the region's schools of public health, Federal health agencies led by Region 1 of the DHHS, and educators, legislators, and representatives from industry, labor, and volunteer associations that focus on health concerns. NECON was established in 1980; in 1986, the New England Governor's Conference charged NECON to work with the State's chief health officers and other health policymakers throughout New England and to prepare annual recommendations for improving the region's health status. The organization has used this charge as a rallying point around which to marshal the economic, political, and public will to prevent disease and improve the region's health.

Through interactive task force working groups, NECON addresses strategies for primary and secondary prevention of cancer, heart disease, stroke, and HIV/AIDS, as well as prevention and health promotion initiatives in mental health, women's health, managed care, and initiatives specifically targeting the medically underserved. The cancer prevention and control work group is a collaboration between the New England Division of the ACS and NECON.

NECON embraces the primacy of prevention, not because it saves money, but because it prevents suffering, enhances quality of life, and improves the efficiency of society.

Key Points

- Last year, prevention initiatives for the region were presented to the New England Governors' Conference. Governor King (Maine), the conference chair, challenged NECON to return this year with a short list of specific recommendations to engage communities, States, and the region in prevention activities. Governor King indicated that the recommendations will be implemented with the support and leadership of the region's governors.
- Nearly 300 policymakers, legislators, and health professionals convened at the Institute for Health Policy at Brandeis University to interact with NECON's task force work groups. Consensus was achieved around six recommendations that will be presented to the Governors on September 22, 2000, in Springfield, Massachusetts:
 - Use the proceeds of the tobacco tax and Settlement funds to establish or expand health promotion and disease-prevention initiatives, including smoking prevention programs that meet CDC guidelines.
 - Combat the epidemic of obesity through initiatives to increase the proportion of each State's population that consumes a nutritionally appropriate diet and is engaged in daily physical activity.
 - Develop an agenda to eliminate by the year 2010 the wide racial and ethnic disparities that currently exist.
 - Extend State-subsidized insurance (with mental health priority) to uninsured, low-income working adults to include screening and preventive services proven to be effective.
 - Increase program funding for violence prevention.
 - Establish and expand school and community-based health programs providing comprehensive preventive health services and health education to children and adolescents.

- The annual NECON conference, *Forging Partnerships for a Century of Prevention*, will convene October 18, 2000, at Brandeis University to focus on implementation strategies for the six prevention recommendations above. Panels consisting of the region's health officers and legislators will deliberate on the recommendations and action plans will be developed to guide implementation. NECON will convene State health action forums that include local medical societies, the managed care community, voluntary organizations, and public health agencies to facilitate implementation of the recommendations at local levels. Next year, NECON plans to establish annual regional recognition awards for communities that develop innovative and effective prevention programs.

REMARKS—MS. LAURIE STOREY-MANSEAU, AMERICAN CANCER SOCIETY

Background

ACS is the nationwide community-based volunteer health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy, and service delivery. A primary objective of the ACS is to reduce the burden of cancer among minority and medically underserved populations. Nationwide, more than 18 million volunteers and supporters, many of whom are cancer survivors, contribute their time and resources to ACS and its mission.

New England is a very rural region with large, remote areas populated by the working poor. According to the 1998 U.S. Census, 11 percent of New England's population lives in poverty, and 12 percent are uninsured. Within the past year, two of the region's largest HMOs dropped coverage for subscribers in the Northern Tier States. Nearly 9 percent of the region's female population is over 65 years of age, and 6 percent of males are over age 65. Of the women aged 40 and older, nearly 1 million have never had a mammogram.

Key Points

- ACS goals for the next decade are to reduce premature cancer deaths by 50 percent and by 2015, to reduce cancer incidence by 25 percent. These goals are potentially attainable based on evidence confirming that approximately 70 percent of all cancers are preventable. Approximately 60 percent of all cancer patients survive at least 5 years. The evidence of decreasing cancer mortality is encouraging and presents a compelling argument for accelerating national investment in prevention, early detection, and scientific research.
- Higher cancer incidence and death rates among minority and medically underserved populations suggest that not all Americans benefit equally from scientific breakthroughs and cancer prevention and control efforts. Minority and poor Americans have a disproportionate risk of being diagnosed with and dying from certain types of cancer. According to the National Center for Health Statistics (NCHS), New England has one of the highest cancer morbidity rates of any region in the country, and African Americans carry a heavier cancer burden than other populations in the region. This year, 66,000 new cases of cancer are anticipated in New England, with nearly 30,000 cancer deaths.
- Despite the large sum of money our Nation spends on health care (\$1 trillion), only 1 percent supports population-based prevention research—less than one penny per person per day. Existing cancer-fighting and prevention tools are effective, but either are not being used or not available to all Americans. Increased prevention and early detection efforts, particularly those targeting medically underserved communities, can reduce cancer mortality and related suffering by preventing its occurrence in the first place; when cancer does occur, it will be detected in its earliest and most treatable stage.

- Lack of health insurance is a significant barrier to obtaining medical care. One in seven Americans is uninsured. Other barriers to receiving quality health care include geography, language, fear, distrust of health care providers, and the difficulties of navigating the health care system.
- Although at first glance it may appear that New England is a highly educated, industrialized region with an abundance of excellent medical institutions and resources, in fact, the region shares all of the cancer prevention and cancer care barriers evident in other parts of the country. Patients living in rural areas of the region often experience difficulties in accessing treatment because of the need to travel great distances. Some patients, such as bladder cancer survivor Mike Pelletier (who was scheduled to provide testimony at this meeting), have overcome geographic barriers to care by accessing Air Lifeline, a free, volunteer flight service provided through a partnership with the ACS to patients living in remote parts of New England. It is likely, however, that many New England residents fail to receive timely diagnosis and treatment because of where they live and their lack of knowledge about available support services such as Air Lifeline. Ensuring access to care is a crucial factor in preventing premature cancer deaths.
- The ACS is actively engaged in advocacy efforts designed to positively impact the lives of cancer patients and their families. Volunteers deliver the message to policymakers at Federal, State, and local levels. At the national level, ACS calls upon Congress to ensure that resources are provided for culturally sensitive programs targeting medically underserved populations. This year, the ACS and its allies advocated for increased resources for NIH treatment research, diagnostic tools, and early detection methods for all Americans. The ACS also expressed strong support for greater minority representation in clinical trials; every American should have an equal opportunity to obtain what may be the only available lifesaving treatment for his or her condition.
- Cancer screening and early detection are effective in preventing cancer (e.g., colon cancer), extending life, and improving quality of life for cancer patients. More than half of all cancers occur in parts of the body that can be screened, such as the breast, cervix, prostate, colon, and rectum. Moreover, the 5-year survival rate for many of these cancers is approximately 77 percent. This rate would increase to more than 95 percent if all Americans participated in cancer screenings. This goal can be achieved within our existing public health infrastructure.
- Part of ACS's advocacy efforts have been directed toward increasing support for the CDC Breast and Cervical Cancer Early Detection Program that provides screenings to poor and low-income women, almost 50 percent of whom are members of racial and ethnic minorities. Currently, only 12 to 15 percent of eligible women are served by the program nationwide. Legislation is under consideration to provide incentives to States (in the form of Federal matching funds) to provide temporary Medicaid coverage to women whose breast or cervical cancer was detected through the screening program. If the bill passes, States will have to apply to the Federal Government to receive this additional treatment funding.
- ACS goals for the coming year include recruitment, training, and coordination of 20,000 Tell A Friend volunteers who will attempt to contact 56,000 older women to encourage regular screening mammograms. Currently, baseline mammography screening rates for the rural Northern Tier States are significantly lower than for other States in the region.
- HRSA-funded programs such as the Community Health Center (CHC) program and the National Health Services Corps are essential elements in health care delivery for the uninsured and those living in medically underserved areas. ACS is working in partnership with CHCs to serve Americans with unmet health care needs who are at increased risk for cancer.
- For the past 3 years, the ACS has been working with the mayor of Boston and the Boston Health Commission on Boston's Crusade Against Cancer project. Through a collaborative effort between ACS and all of the hospitals and health centers in the city, every Boston resident now has access to cancer screening and state-of-the-art care. City workers receive time off to obtain screenings and ACS

cancer control guidelines are a pivotal program element. This initiative has been lauded by the U.S. Conference of Mayors and other cities, including New York. Program replication in other cities is currently under consideration.

- ACS continues its aggressive advocacy for tobacco control and prevention at State and local levels. ACS advocates distributing tobacco master settlement agreement funds to disenfranchised communities where the tobacco industry continues to have a major presence. Smoke-Free New England, an ACS-sponsored collaborative effort, is designed to accelerate the momentum against tobacco use and raise tobacco taxes in all six New England States. Funds will be used to increase tobacco control efforts and to increase health care access for all citizen in the region. Simultaneously, ACS is advocating stronger restrictions on youth access to tobacco and an increase to 30 percent in the number of New England school systems with comprehensive school health programs.
- ACS's recent experience conducting a regional community needs assessment in New England illustrates the consistent lack of population-based data due to severe underfunding of State cancer surveillance. For example, the State of New Hampshire was able to survey only 1,500 residents about their lifestyles and cancer screening practices. Conclusions from the survey data were based upon a sample of 0.14 percent of the population; extrapolating the data to the entire population was of questionable validity. Increased funding for the Behavioral Risk Factors Surveillance Study (BRFSS) and the Youth Risk Behavior Study would provide an opportunity to more accurately assess the population in New England. Success in addressing the unequal burden of cancer among minorities depends greatly on the availability of high-quality and reliable data.

Recommendation

- Data collection and surveillance efforts through national and State-based cancer registries must improve. Registries are incomplete, and the experience of racial and ethnic minorities is underreported. Therefore, it is extremely difficult, if not impossible, to develop reliable estimates of the cancer burden in New England or to predict trends that will guide cancer control efforts. Funding for State surveillance efforts must be increased.

CONNECTICUT

Presenters:

Dr. Nancy Berger
Ms. Susan Anderson
Ms. Marilyn Moore
Ms. Penny Blazej
Ms. Linda Fisher

DR. NANCY BERGER

Key Points

- The disconnects between discovery and delivery often are gaps that are not filled and changes that are not made based on new knowledge. The reasons these gaps and stases exist are numerous and intertwined. Economic and political environments, social norms, and personal attitudes and knowledge are challenges to resolve, but their interconnectedness adds a degree of complexity to efforts to resolve the issues and problems.
- Efforts must be targeted to those most vulnerable (e.g., those with limited income, minorities, non-English speaking populations, those with transportation issues), but all Americans are

underserved in the sense that everyone is affected by what we are not accomplishing in the war on cancer and other major diseases.

- The principal categories of issues preventing people from getting appropriate care are: knowledge and beliefs; financial, emotional, and social supports; and political, public, and personal will.
- The most effective way to approach some of the policy, legislative, and infrastructure issues in cancer care is to develop nontraditional partnerships among a diverse array of people and organizations. For example, the Marriott Corporation announced its plan to build a new childcare facility in the Washington, DC, area; one of the services they plan to provide is mammography. Many organizations are looking at their mission more globally and are trying to identify how they can provide a broader array of nontraditional services to their local communities. Similarly, health care organizations can be proactive in their dealings with non-health care organizations regarding issues in cancer prevention, control, and treatment access. Organizations can be encouraged to provide health insurance benefits, adopt healthier work environments, and support screening and early detection programs.
- The need to listen to the public, especially to local communities, about what they need in the way of cancer care cannot be underestimated. Community-based assessments and outcome data must be used to drive the development of appropriate policies and programs. The Clean Air Act legislation provides an example of how policy and program development can stem from a community assessment. Prior to its enactment, the major argument against the legislation was that instituting clean air policies in schools, work sites, restaurants, bars, and other public places would result in economic losses. This did not happen; patronage was maintained and employees' lung capacity improved.
- Legislation and nontraditional policy development can be used to stimulate health-related behavioral change such as including high school physical education requirements as a graduation prerequisite or requiring health insurers to offer coverage for nutritional counseling, smoking cessation, and other prevention and early detection services. By presenting data demonstrating that exercise enhances productivity and quality of work, employers may be encouraged to provide time for employee exercise during the work day.
- Unless the infrastructure needed to support new policies is in place, policy changes are unlikely to achieve their objectives.

MS. SUSAN ANDERSON

Key Points

- Patients who wish to join clinical trials encounter the same access barriers as those seeking access to general health care.
- The level of participation in clinical trials varies by disease and the perceived need for research on a particular disease. Several years ago at Yale University, participation in clinical trials for patients with multiple sclerosis was extremely high, requiring little recruitment effort, because little was known about the disease and the trials provided one of the first opportunities to receive treatment. Attempts to fill adult oncology-related clinical trials, however, have been far less successful.
- Children with cancer are far more likely to participate in clinical trials; currently, 70 to 80 percent of pediatric oncology patients are enrolled in trials. However, the pediatric clinical trials model cannot necessarily be applied to the adult population, as many have suggested. Cancer in children may be biologically different from adult cancers, and children may be more responsive to chemotherapy. Because cancer in children is relatively rare, these patients are more likely than adults to be referred for care in academic medical centers. To accrue enough patients to make statistical analysis of

treatment options possible and increase the body of knowledge about childhood cancers, pediatric oncologists have been forced cooperate and to pool patients and data.

- The American Society of Clinical Oncologists (ASCO) surveyed 3,500 oncologists to determine the reasons for their lack of participation in clinical trials. Excessive paperwork demands that disrupt physicians' daily routines and often become overwhelming were cited as a principal barrier to participation.
- Community-based oncologists may fear losing their patients to the academic medical centers; this does occur at times. The treatment process is simplified for both the patient and the physician when treatment is provided at the same institution that is responsible for clinical trial monitoring, but when academic physicians do not reliably send the patient's medical reports back to the referring physician, the patient becomes disconnected from his or her original, community-based oncologist. Moreover, community-based oncologists have little incentive to conduct research. They are focused on delivering care in a managed care environment in which productivity pressures are severe. In addition, community-based oncologists who participate in clinical trials may deviate from the rigid structure of the treatment protocol, exercising independent medical judgement when they believe it is indicated. However, patient data are lost to the study when this occurs.
- Clinical trial participation also may be affected by the fact that many patients have been lulled into accepting current standard treatments for common cancers as the best care they are likely to receive. To increasing clinical trial participation, patients and physicians must believe that better care is both needed and possible.
- Patients still fear that if they participate in a clinical trial, they will be used as medical "guinea pigs." There is a general lack of trust of the medical profession and a belief that physicians conduct research to advance their careers. These concerns are compounded by intense fear of cancer. In addition, many patients are relatively uninformed about cancer treatment options and may reach unwarranted conclusions about an entire class of treatment (e.g., that chemotherapy is the same for all types and stages of cancer). Patients also fear they may be assigned to receive only a placebo.
- Newly diagnosed cancer patients typically experience anger and confusion. At the same time, they are bombarded by information from multiple sources—their physicians, the Internet, relatives and friends, television—and need assistance in evaluating this information and in finding and accessing an appropriate clinical trial. Many patients learn about the possibility of participating in a clinical trial only after their disease has become advanced. In New England (and perhaps elsewhere in the country), the perception is that one goes to a major cancer center only when other treatment options have been exhausted. It is very difficult to get newly diagnosed patients in rural areas into the cancer center for initial treatment.
- Other barriers to clinical trials participation include costs and the struggle to secure payment for trial costs, fragmentation of care when patients must see many specialists and providers in the course of their care, and regulatory requirements. Following a number of recent incidents in which trial participants were harmed (or died), reporting requirements and monitoring for compliance with Federal regulations concerning human research subjects have escalated sharply.

Recommendations

- Outreach and education should be focused on healthy people to increase their understanding of how to access the health care system when a catastrophic illness such as cancer occurs.
- Additional funding should be provided to strengthen existing comprehensive cancer centers, since they have the necessary infrastructure to provide multidisciplinary care, are accustomed to complying with research oversight and audit requirements, and are mandated to conduct outreach which currently is underfunded in the community setting.

MS. MARILYN MOORE

Background

The Witness Project in Bridgeport, Connecticut, a breast and cervical cancer education program for African American women, is conducted in churches and community centers by Witness role models (African American breast and cervical cancer survivors) and lay health advisors. The role models provide proof that cancer is not a death sentence. The lay health advisors, though not cancer survivors, organize and publicize programs, network with the community, and provide information about screening services and available resources. They teach breast self-examination and encourage use of early detection tests such as mammograms, clinical breast and pelvic exams, Pap tests, and breast self-exams. Of the 23 volunteers in the Bridgeport area, 14 are breast cancer survivors.

During a typical Witness program presentation, two to five Witness role models discuss their cancer experience, sharing their fears and concerns while stressing the importance of early detection.

Key Points

- African Americans have the highest overall age-adjusted cancer incidence and mortality rates of any U.S. population group. Despite a somewhat lower incidence rate, the 5-year survival rate for African American women with all stages of breast cancer is markedly lower than the rate for Caucasian women.
- African American women are twice as likely to develop cervical cancer and nearly three times more likely to die from it. Poor, minority, and elderly women (particularly those in rural areas) are less likely than other women to participate in cancer screening. Barriers to participation in early detection efforts include cost, lack of insurance, transportation problems, inconvenient locations and schedules, lack of time, lack of physician recommendation, fear and fatalistic attitudes about cancer, lack of knowledge, and misunderstanding of recommended screening schedules.
- To improve the effectiveness of community education and outreach, the Witness Project uses culturally appropriate materials (supplied by the NCI and ACS) including breast models that are specific to women of color. Mobile mammography and support services also are provided.
- The Witness Project also developed the first African American support group for women in Connecticut that provides both emotional and financial support. The project developed linkages with other organizations such as Cancer Care and the ACS to fund treatment for uninsured women. In addition, the project refers uninsured women to the Connecticut Breast and Cervical Cancer Program to obtain free mammograms. The project has returned to some community and senior centers three times to provide education and rescreening. Since its inception in 1998, the Witness Project conducted has 55 programs and reached 1,168 women; 820 of these women were over 50 years of age.
- When family income is limited, many parents focus first on meeting their children's needs and rank their own health care needs as a lesser financial priority. This is especially true in the case of mammography and other cancer screening services, particularly in the absence of symptoms.
- Too often, community health education is conducted to raise awareness of breast cancer and to promote annual mammograms, yet mammography is not universally accessible, either because it is too costly or because the technology is not available in certain locations.
- No blueprint or strategic plan appears to exist to direct or coordinate NIH/NCI research activity related to cancer health disparities experienced by minorities and the medically underserved, nor is there sufficient funding to address the needs of these populations.

Recommendation

- At the State level, a well-defined plan of financial or program referral assistance is needed to help women access cancer education and screening services. Changing behaviors and attitudes has no value if there are no services in place to support the change.

MS. PENNY BLAZEJ

Background

The Center for Hope, located in Darien, Connecticut, is a not-for-profit organization supported by the local community. It provides counseling services and case management for anyone who is seriously ill, their loved ones, and family members; bereavement support is also available. The Center for Hope has focused on serving the working poor, illegal immigrants, legal immigrants who lack health insurance, and the elderly—particularly those who lack Medigap coverage, those enrolled in a managed Medicare plan, the terminally ill in skilled nursing facilities, and those 80 years of age and older.

Key Points

- The State of Connecticut sponsors an emergency health insurance program, referred to as SAGA, through which uninsured low-income people with major illnesses can receive health care coverage. SAGA eligibility guidelines include a residency requirement of at least 6 months and legal immigration status. People who have depleted their assets as a result of a catastrophic illness or chronic disease also are eligible. There is also concern about those who need help before the 6-month qualification is met.
- The elderly aged 80 and older face a unique form of discrimination. They may be denied services they want (e.g., an operation) because they are perceived to be too old. When they choose palliative care, however, they may be forced into receiving treatment they do not want.
- There are a number of key deficiencies in third-party payer programs. For example, the Connecticut Medicaid program does not cover breast reconstruction following a mastectomy, alternative medicine techniques, or hospice care for people under 65 years of age. The lack of coverage for inpatient (residential) hospice is a glaring omission, because many of these patients with terminal cancer have no one in the home to provide care for them.
- Medicare does not cover prescription drug costs, which results in major out-of-pocket costs for the chronically and terminally ill. Patients may appear to be noncompliant with recommended treatment regimens, but they forego treatment because they cannot afford the medications. Medicare reimbursement of skilled nursing facilities is inadequate to cover the cost of cancer treatment. Patients discharged from hospitals while still receiving chemotherapy and radiation often require admission to a skilled nursing facility, yet the skilled nursing facilities are reluctant to admit them because of recent reductions in Medicare reimbursement rates. In most cases, they stay in the hospital, increasing the cost of care.
- The loss of income during treatment is an unrecognized cost of cancer. For the underserved who need two incomes to cover family expenses and for single parents, loss of income represents a major burden of the disease. As people survive longer with cancer, these financial issues become longer-term and even more significant.
- Cost-control pressures have resulted in the elimination or reduction of clinical social workers in clinics and cancer centers. This has adversely affected patient education and cuts the link by which referrals to community-based support organizations or agencies normally are made. Lacking these referrals, the underserved become even more so.

- Current regulations specify that a hospice team cannot attend to a patient in a skilled nursing facility because doing so creates an overlap of skill; this is incorrect. Skilled nursing facility staff have neither the expertise nor the time to provide for pain management or end-of-life care and counseling of both the patient and family.

Recommendations

- Increase political pressure to defeat the proposed decreases in Medicare reimbursement for outpatient oncology, particularly chemotherapy. This policy is scheduled to take effect October 1, 2000.
- Expand Medicare and Medicaid benefits to include coverage for residential hospice care, which is less expensive than either inpatient hospital care or a skilled nursing facility and provides a more supportive atmosphere during the dying process.
- The Federal Government should provide emergency medical coverage for the working poor, no matter how long they have lived in a State.
- Medicare hospice benefits should include reimbursement for medications, counseling, and spiritual support. In-home hospice reimbursement has declined so significantly that not-for-profit hospice organizations have been forced to eliminate many positions, particularly those involved in providing psychosocial support.
- Culturally sensitive national educational programs are needed; education on the value of advance directives is particularly crucial.
- Physician education is needed to encourage sensitive communication about prognosis and timely referrals to social service and health agencies that can provide end-of-life support.

MS. LINDA FISHER

Background

Ms. Fisher is a registered nurse and a colon cancer survivor. Despite her health care background, she failed to recognize the symptoms of colon cancer and, therefore, experienced a delay in diagnosis and treatment. In 1995, she began to notice blood in her stool but attributed it to hemorrhoids, which she had had in the past. She mentioned this symptom to her primary care doctor during a routine physical examination; he performed a digital rectal exam (DRE) and fecal occult blood test (FOBT), both of which were negative. The doctor concurred that the bleeding probably was caused by internal hemorrhoids and did not refer Ms. Fisher to a gastroenterologist. Under her health plan, she could not seek a specialist's opinion without a referral. Since the doctor's assumption seemed reasonable, Ms. Fisher accepted the diagnosis.

She continued to notice small amounts of blood in her stool, but as there were no other changes, she did not again mention it to her doctor. She was 42 years old at the time. Over the ensuing 2½ years, however, she began to notice episodes of constipation alternating with periods of bowel urgency. These changes took place so gradually that she attributed them to stress, consumption of different foods, changes in schedule, and other reasons. By the fall of 1998, she knew something must be wrong. Even so, she did not seek care until January 1999 because she was afraid of interrupting the holiday season for her family. In addition, she was not comfortable with her doctor, feared the testing she knew would be ordered, and was afraid of a possible cancer diagnosis.

She had to wait nearly 3 months for an appointment with a gastroenterologist, although she explained her symptoms when making the appointment. Ms. Fisher felt optimistic, since no one seemed to think it urgent that she be seen. She finally had a sigmoidoscopy, which found a single polyp; the doctor was

clearly concerned but was hesitant to answer her questions and did not provide any additional information on bowel polyps or colorectal cancer. In a state of confused panic, she was sent home.

Ms. Fisher began to look for information on colon cancer. She contacted a nurse she knew who had been diagnosed with the disease 4 years earlier and sought information at the local bookstore. The following week, Ms. Fisher had a colonoscopy, at which time the polyp was removed. It was malignant, but a CT scan showed no evidence of metastasis. By this time more educated about the disease, Ms. Fisher underwent a colon resection in April 1999; fortunately, the cancer had not invaded the bowel wall, and her lymph nodes were negative.

Key Points

- When detected early, many cancers can be treated successfully with minimal disruption to one's lifestyle and body image. However, some cancers are more difficult to detect in the early stages because they often do not produce recognizable symptoms until the disease is advanced. Colon cancer is avoidable, yet it is the second most common cancer killer in the United States.
- As a nurse, Ms. Fisher had access to information and resources not available to many people, yet the disbelief, fear, and grief she was experiencing was like that experienced by most newly diagnosed patients. These feelings can significantly hamper a person's ability to find and absorb information and to make potentially life-altering decisions about their health care.
- Health care providers do not adequately prepare cancer patients to make the type of health care decisions that arise during the course of the disease. It is cruel to allow frightened patients to flounder without the tools to support informed decisionmaking about health care options. The diagnostic process is far too lengthy, causing patients to endure excessive anxiety as they await numerous test results.

Recommendations

- Increase public awareness of all types of cancer screening efforts and treatment options.
- Encourage the medical community to recommend that adults obtain colonoscopies prior to age 50, even if they are asymptomatic and lack a family history of colon cancer.

DISCUSSION—STATE OF CONNECTICUT

Key Points

- Mobile screening units play a particularly significant role in expanding community access to mammography. Many women are so afraid of being diagnosed with breast cancer that they avoid having a screening mammogram. Strong emotional barriers must be overcome for many women to seek prevention/detection services. Mobile mammography units provide an opportunity to bring the service directly into the community, thereby breaking down some of the traditional health care access barriers. The mobile units are usually staffed with people who are accustomed to providing outreach, education, and supportive services. This staffing pattern tends to make patients feel more comfortable about their decision to participate in the screening effort. It sometimes is necessary for a staff person known to the patient to accompany her into the van's mammography booth in order for her to go through with the test.
- Relying on mobile units to provide the bulk of mammography at the community level is risky, since women cannot count on the availability of the units. The mobile vans are owned by local hospitals that establish their own criteria for access and determine the van's travel schedule. For example, the van owned by Yale University does not provide mammograms for the uninsured. The fact that mobile

units exist in a community does not necessarily ensure access—in response to political pressure, a mobile screening unit based in Stamford, Connecticut will no longer travel outside its immediate service area to provide care. Previously, the van traveled 72 miles to Hartford and provided a considerable number of mammograms to Hartford women.

- Numerous cultural barriers must be overcome to improve access to care. Attitudes about cancer vary considerably across ethnic groups that profoundly affect people's willingness to engage in prevention/detection activities and to seek treatment. For example, low-income Hispanics tend not to participate in cancer screening because they do not wish to face the possibility that they may have cancer. They also are afraid to seek treatment for fear that treatment may prevent them from providing financial support to their families and that paying for treatment will pose undue financial hardship on the family. In low-income African American communities, there is a tendency to resist counseling of any kind because it is associated with psychiatry, which carries a social stigma. Social workers often focus first on resolving the patient's financial issues, since in doing so they establish a relationship that may serve as the foundation for providing emotional support.
- It is particularly difficult to implement primary prevention efforts that target behavioral changes in large populations, but it can be done. In Connecticut, children's soccer teams have incorporated the application of sunscreen into their pregame preparations. This practice reinforces the importance of preventing skin cancer generally and engages the family in ensuring that the child has access to the sunscreen.
- Consideration should be given to broadening the focus of existing cancer screening programs and permitting more flexible use of categorical funding. Many women who present for mammography are at the age at which a colon cancer or cardiovascular health screening is also recommended. Opportunities to reach people with important early detection services are being lost because of current restrictions in the use of funds.
- More public education about clinical trials is needed. People are confused about the nature of clinical trials and how patients can participate in them. The NIH Web site is an excellent source of information about the clinical trials process; this information should be widely disseminated and discussed with patients.
- There is a tremendous need to improve cancer information dissemination efforts nationwide. Excellent information materials are produced by NCI and the CDC, but cancer centers are not permitted to use their funds for information dissemination to the community. However, numerous community-based organizations, business leaders, pharmaceutical companies, and other institutions are willing to go into the local communities to perform outreach and education without charge.
- Studies are underway to identify effective approaches to public education about clinical trials. Because so little research has been conducted in this area, organizations currently involved in clinical trial information dissemination are urged to include an evaluation component to help determine which dissemination strategies and techniques work best.
- Managed care erects many obstacles to health care access, among them limits on access to care and physician choice. Patients often are restricted to using physicians who are members of the HMO's provider panel, and do not have access to specialists of their choice. HMOs also restrict access to certain medications, particularly expensive chemotherapy medications, and do not provide coverage for patients who wish to participate in clinical trials, especially the elderly. Most HMO enrollees are unaware of their right to appeal health plan decisions about their care; even when they are aware, they often do not avail themselves of the opportunity because the appeal process is too difficult. Generally, the appeal process requires the support of a patient advocate such as a clinical social worker as well as the involvement of other medical professionals who already are overburdened by health system pressures and demands.

- Extensive regulation and oversight of the managed care industry is needed. As more people turn to litigation to resolve their difficulties with managed care, some changes may be made to ensure that access to services and providers is not compromised. In the current setting, institutions have had to hire additional staff just to deal with the managed care plans and attempt to secure reimbursements.
- The President's executive order requiring that Medicare reimburse patient care costs associated with clinical trials is scheduled to take effect October 1, 2000.

NEW YORK

Presenters:

Dr. Mark Baptiste
Dr. Jacques Lipson
Dr. Jerome Yates
Mrs. Ann DelleDonne
Mr. Richard Farrell

DR. MARK BAPTISTE

Background

Cancer is a serious problem in New York; according to the State cancer registry, 85,000 new cases of cancer are diagnosed each year (occurring equally among males and females) and 38,000 cancer deaths. New York is a large and ethnically diverse State. Its population numbers more than 18 million people, with more than seven million people concentrated in New York City. Many people think only about the small geographic area of New York City when thinking about New York as a whole, however, the majority of the State is quite rural and shares many of the health care access problems of the northern New England States.

Key Points

- Numerous effective screening tests for colorectal cancer exist (e.g., FOBT, endoscopy, colonoscopy, sigmoidoscopy). Research has demonstrated that colorectal cancer morbidity and mortality decrease when people participate in screening for this disease, yet only 33 percent of New York residents have ever had a FOBT and even fewer have had a colonoscopy.
- People resist FOBT for several reasons—they believe they already are sufficiently knowledgeable about colon cancer, they do not believe the test is necessary, they do not need the information, they do not believe they are at risk for the disease, or they believe are too busy to perform the test. State cancer diagnosis data show that the number of colon cancer cases diagnosed at early stages has not increased, reflecting the low screening levels in the general population.
- The underserved and vulnerable populations in New York include the poor, the uninsured, the poorly educated who lack access to good cancer information, rural residents, and minorities.
- Although breast cancer incidence is much higher among white women than among black women and other ethnic minority women, the breast cancer mortality rate of black women is equal to that of white women. This disparity raises serious questions about the stage at which breast cancer is detected in different populations and about variations in access and quality of care. In 1980, cancer registry data indicated that less than 50 percent of white women were diagnosed with early stage breast cancer, but less than 40 percent of black women were diagnosed with early stage disease. Since 1980, early detection has improved in both populations, but early detection of breast cancer in white women (just

under 70 percent of breast cancer cases) remains much higher than in black women (just over 46 percent). These figures indicated that the disparity in early detection not only persists, it is increasing.

- Cervical cancer incidence and mortality among nonwhite women in New York is much higher than among white women. Virtually all cervical cancer deaths are avoidable if women avail themselves of regular screening.
- New York and the CDC have jointly funded the development of 53 statewide Healthy Women Partnerships to provide breast and cervical cancer screening to low-income, uninsured, and underinsured women who have not previously participated in screening efforts. Special programs have been established to conduct outreach to racial and ethnic minorities. The Healthy Women Partnerships can be headed by a local or county health department, a local chapter of the ACS, a local hospital, or any organization that can achieve program goals at the community level. In the past year, 53,000 breast screenings (which includes a mammogram and a clinical breast exam) and more than 15,000 cervical cancer screenings have been provided through the program. Although this is a significant achievement, a considerable number of eligible women have yet to be screened. Importantly, the partnerships are not limited to screening, but also provide cancer treatment.
- New York is starting a pilot colorectal cancer screening program that will focus on the underserved and the uninsured population aged 50 years and older. The program will include FOBT and community-based education. In addition, the State is supporting a prostate cancer initiative for underserved and older males, with special emphasis on the African American community.
- The Cancer Surveillance Improvement Initiative is underway in New York to map lung, breast, and colorectal cancer by county and zip code. Information collected through this effort will be used to better understand environmental and other risk factors related to cancer and to improve cancer control program planning and development.

DR. JACQUES LIPSON

Background

Dr. Lipson has been a specialist in internal medicine for the last 38 years and is a three-year survivor of lung cancer. Although he was not a smoker and had none of the risk factors associated with lung cancer, he obtained a routine chest x-ray. His only symptom was minor weight loss. The x-ray revealed the presence of a mass in the upper lobe of one lung. Within a week, he received CAT scans of the lung, abdomen, and brain and underwent biopsies of the lung and surrounding lymph nodes. Test results indicated that he had stage 3B lung cancer, with bilateral lymph node involvement. Within two weeks, he began a rigorous and difficult course of “sandwich” chemotherapy, consisting of six weeks of cisplatin and navelbine, six weeks of radiation, and an additional six weeks of navelbine and cisplatin. He has been cancer-free for 3 years but remains very concerned because the 5-year survival rate for his type and stage of lung cancer is only 3 percent.

Key Points

- Government and third-party payers cannot provide the level of funding necessary for cancer centers to flourish and expand. Private philanthropy plays a major role in supporting cancer care and the expansion of treatment facilities. When contacted by the cancer center at which he received treatment to donate money to support a major renovation, Dr. Lipson agreed, but on the condition that specific things were done to improve the patient care experience. These included building private rooms for patients who are sick and vomiting, expanding the number of lavatories, including an on-site pharmacy, and incorporating a number of esthetic elements into the design to create a more patient-friendly environment.

- Third-party reimbursement practices continue to be barriers to preventive health care. Up until a year ago, the Federal Government did not cover prostate-specific antigen (PSA) screening unless a man had a prior diagnosis of an abnormal digital rectal exam or an elevated PSA. Patients without the correct diagnostic codes who received a PSA at the hospital would be billed \$40 to \$60 for the test. Similarly, patients without a prior diagnosis of diabetes, heart disease, or high blood pressure would be billed for diabetic screening.
- Medicare and HMOs in Rochester, New York, do not cover routine screening colonoscopies because of the high cost of the procedure. Sigmoidoscopy, which generally is authorized if a patient has repeated positive FOBTs, misses 30 to 50 percent of colon tumors because it does not examine a significant portion of the bowel. HMOs discourage routine x-rays.
- The Patient Bill of Rights is worthy of support, however, health care-related conflicts should not be resolved through the legal system. Legal involvement escalates the cost to the entire health care system and drains funds from the delivery of health care services. Instead, panels of impartial mediators and medical experts should be convened for conflict resolution within 2 to 4 days of notice of a claim. This will enable patients to receive help more quickly and avoid a lengthy and costly litigation process.
- Patient noncompliance and resistance are among the most significant barriers to health care. What can be done with a patient who will not make or keep a medical appointment and who is unwilling to engage in recommended cancer screening procedures?
- HMO capitation rates are too low, and do not seem to be developed with an understanding of the real costs of care. Health care costs have increased considerably, not because of a rise in primary care physician salaries, but because of increasing pharmacy, technology, and specialty care costs.
- Large employer groups and managed care companies also are responsible for creating barriers to health care. In negotiating health care coverage for their employees or enrollees, they place increasing pressure on the health care providers to contain cost by paying providers on a capitated basis and then withholding as much as 15 percent of the capitation; should the health plan break even or make a profit on a capitated contract, some or all of the withheld dollars are paid to the provider group. Providers are thus placed in the untenable position of needing to respond to patient demands for services with fixed resources that are additionally reduced by the withheld amount. In this situation, providers rarely obtain 100 percent of the negotiated capitation rates and therefore are providing services at a coerced discount.

DR. JEROME YATES

Background

The Roswell Park Cancer Institute recently purchased a gamma knife, a tool that provides highly focused radiotherapy for patients with certain types of brain tumors. This technology is extremely expensive (\$3 million) and the cost per procedure is approximately \$15,000.

The purchase of this equipment and the Cancer Institute's decision to open access to the technology to the entire medical community has resulted in an unprecedented level of collaboration among medical specialties. Every other week, community neurosurgeons, neurologists, oncologists, radiotherapists, and the Institute's neurologist convene to discuss patients potentially eligible for the gamma knife procedure. This collaborative effort has been so successful that it has become common for the specialists to seek consultation on patients who clearly are not candidates for the gamma knife, but whose health care issues require a multidisciplinary solution. The collaboration has also resulted in a high level of quality assurance, since potential gamma knife cases are reviewed in detail by a team of specialists. Further, the biweekly conferences provide a valuable forum for continuing medical education.

Local insurers (both managed care and indemnity) have benefited from this medical collaboration because they have not felt the need to assign gatekeepers to monitor the use of the gamma knife technology. The lack of gatekeepers saves the health plans money, provides them with a level of expertise they did not have previously, and provides the physicians with more independence in their practice.

The collaborative approach to purchasing and utilizing such expensive equipment has enhanced the quality of care provided, the level of research conducted, and has enabled the providers to remain free from potential government health planning agency intervention.

MRS. ANN DELLEDONNE

Background

Mrs. DelleDonne is from Rochester, New York. In March 1996, her husband was diagnosed with pancreatic carcinoma. His primary care physician disclosed the gravity of his condition and indicated that his only chance for survival would involve a surgical intervention. Despite three physicians' recommendations that Mr. DelleDonne be treated at the Roswell Park Cancer Institute due to the seriousness of his condition and the special expertise available at the Institute, the referral was denied by his HMO. Despite the denial, the DelleDonne family decided to seek a second opinion at Roswell Park. After meeting with an upper gastrointestinal surgical oncologist and discussing a recommended course of action, it became clear that there were treatment options that had never been discussed by physicians at the local hospital in Rochester. Yet the HMO refused to pay for care rendered outside its provider network. Mrs. DelleDonne attempted repeatedly but without success to obtain information about the local hospital's experience and mortality rates associated with the procedure that Mr. DelleDonne was supposed to receive. The hospital's refusal to provide this information convinced the DelleDonnes that seeking care at Roswell Park had been the right decision. At one point in the process, Mr. DelleDonne's referring oncologist in Rochester was reprimanded by the HMO and threatened with the loss of his position as a board member for his continued efforts to appeal the HMO's denial of the DelleDonne's request.

Ultimately, surgery was performed at Roswell Park, resulting in diagnosis not of pancreatic cancer, but a rare and slow growing carcinoid tumor originating in the bile duct. As the medical bills mounted and the HMO denials continued, the DelleDonnes filed suit against the HMO, which ultimately agreed to pay for the medical services rendered at Roswell Park as well as for follow-up care.

Despite the success of Mr. DelleDonne's initial surgery, the cancer returned after 4 years with liver metastasis. The HMO continued to deny requests for the testing and office visits Mr. DelleDonne required. Further, the HMO indicated that given the liver metastasis, no further treatment would be indicated. Refusing to accept the HMO's assessment, the DelleDonnes used the Internet to locate a small number of physicians who specialized in treating this rare cancer, however, none of these physicians was a member of the HMO's provider network. The DelleDonnes selected a carcinoid specialist located in New York City, and in preparing for the appointment obtained Mr. DelleDonne's full medical record. They discovered that a possible liver metastasis was noted in his CAT scan report a year previously, however, he was not informed of it. Despite the HMO's denial of claims associated with his ongoing treatment, Mr. DelleDonne has continued to obtain treatment from the out-of-network specialist. Through their contact with this carcinoid specialist, the DelleDonnes learned that a particular blood test could have been performed following his initial surgery to detect metastasis even before it was visible on the CAT scan. Because the DelleDonnes were denied access to carcinoid specialists, the metastasis went undetected and untreated. Had the referral been granted, treatment could have been initiated much sooner.

Key Points

- The single most significant barrier to obtaining the best available cancer care is the managed care industry. No one should need to hire an attorney to ensure that adequate health care services are provided to patients, whether it is provided within the HMO's network or not.
- Medical decisionmaking should be left up to the treating physician and the patient, rather than a HMO medical director who does not have direct contact with the patient.
- It is a very serious situation when patients are unable to obtain care outside of their managed care network, even when network providers lack the knowledge and experience the patient needs. When patient care is treated like a financial venture and not as a means to a healthier population, everyone except the HMO executives suffers.

MR. RICHARD FARRELL

Background

Mr. Farrell was diagnosed with colon cancer in 1996. He is from Amsterdam, New York; Amsterdam is in Montgomery County, which has the highest colorectal cancer incidence in the State. To date, Mr. Farrell has undergone four major abdominal surgeries; eight tumors were removed from his colon, muscles, kidneys, and other organs. He has received seven types of chemotherapy and has had nine minor surgeries to place and remove various stents and ports. Currently, he is receiving radiation and chemotherapy in hopes of shrinking a newly discovered abdominal tumor sufficiently to permit its surgical removal.

Key Points

- When you have cancer, you never stop worrying about what's going to happen tomorrow because there is always the continuing worry that you may have a recurrence or a metastasis to someplace else in your body.
- The Internet is an excellent source of information for patients with colon cancer. The Colon Cancer Listserv, a group of more than 600 colon cancer survivors, family members, and friends provides access to information about treatment options and provides ongoing support to people with cancer and their loved ones.
- Mr. Farrell's physicians have sometimes asked him to provide information on colorectal cancer research and treatment that he has located on the Internet.
- Noting the lack of advocacy organizations for people with colon cancer, Mr. Farrell and his associates established the Colon Cancer Alliance, which advocates for the colon cancer patient, survivors, caregivers, family members, and anyone who needs to know more about the disease. The Alliance's quarterly newsletter, "The Voice," is its primary information dissemination tool. One of its first issues was devoted to explaining all aspects of clinical trials and participation in them. The Alliance distributes colorectal cancer literature, provides telephone support to survivors, facilitates a buddy program that pairs survivors of similar cancers, and operates a Web site (www.ccalliance.org) that provides additional information.
- Although colorectal cancer is the second leading cause of cancer death in the U.S., colon cancer research is grossly underfunded. In 1997, NCI provided \$333 million for breast cancer research, \$74 million for prostate cancer research, and \$2.5 million for colorectal cancer research. The Colon Cancer Alliance is working to increase colorectal cancer research funding through legislative processes.

DISCUSSION—STATE OF NEW YORK

Key Points

- Public health resource allocation should be based on as much scientific evidence as possible to ensure that adequate support is provided for interventions that have been proven to work. Political forces also are at play, however, and resource allocation often is affected by the influence of prominent public figures who either have experienced a particular disease or have championed particular issues. Scientists do their best to support legislators' informed decisionmaking on health issues, but ultimately, public servants in the health arena must do as they are instructed.
- Pap smears were known to be an effective public health cancer screening tool for 15 to 20 years before third-party payers agreed that the test should be reimbursable. Colonoscopy screening has been proven to reliably detect colorectal cancer, yet there is third-party payer resistance to reimbursement. Agencies providing colorectal and cervical screening such as CDC and others need to recognize that when patients are uninsured the cost of their treatment may need to be borne by the screening agency.
- Absent a substantial body of evidence about the value of a screening intervention, it is extremely difficult to make the decision to commit large sums of public money to screening programs for healthy populations.
- Political pressure and public awareness tend to be the two most powerful influences on resource allocation for medical research. Resource allocation should be driven by scientific and objective criteria, but the reality is that those who have the most effective public relations efforts generally receive the most funding. Funding for AIDS research provides a well known example of this; likewise, breast cancer research funding was inadequate for many years because of a general lack of public awareness of the disease. As awareness increased, so did funding. Colorectal cancer research, however, still remains a lower priority than other cancers because it is not a "clean disease" and until recently, people have been reluctant to publicize their colorectal cancer experiences. It will take several years of increased public attention to this disease to achieve greater funding for colorectal cancer research.
- The body part-oriented approach to research funding is likely inappropriate; broader, molecular-based strategies applicable to many cancers may prove to be the more appropriate approach to making research funding decisions.
- The rise of managed care occurred because medical care costs were skyrocketing out of control. Under the fee-for-service system, physicians could prescribe and be reimbursed for any type of treatment they wished, without regard to cost. Now our health care system is out of balance to the opposite extreme, with managed care programs playing too dominant a role in medical care decisionmaking and access to care. The need for change is clear, but it is unclear exactly what that change should be and how it should be undertaken.
- From the insurers' perspective, there are only two types of patients in the world—healthy ones who do not need health care and sick ones (who are in the minority) who need health care and consume the majority of health care resources. Third-party payers (both public and private) want to insure the healthy people, since their premiums will not be offset by significant health care expenditures. Employers argue vigorously to retain experience rating, since they are more likely to have a healthy population in which the demand for health services is low, thereby costing considerably less to insure. The sick and the elderly are more likely to need expensive health care; experience rating of these populations drives premiums up. It is our public health responsibility to see that community rating is instituted universally to provide the foundation for an equitable health insurance system.
- Outcome data, such as procedure-related morbidity and mortality, should be collected and disseminated widely to enable patients to make better informed decisions about their health care.

Attempts to obtain these types of data either from hospitals or third-party payers typically have been unsuccessful. Patients are told that the data are unavailable or are given the runaround to discourage them from inquiring. Recent research has shown that the greater the number of procedures performed by a particular provider or hospital, the better the outcome. The National Cancer Policy Board conducted a workshop on the relationship between procedure volume and patient outcome. A report of the Board's efforts will be published shortly, and may prove useful in negotiations with insurers.

- State-level decisionmaking regarding health resource allocation often is influenced by Federal funding priorities; a small State like Vermont, for example, cannot afford to use general funds for screening and so relies on Federal dollars to support screening efforts. States are more likely to allocate health funds for screening if a particular disease is highly prevalent, if screening is relatively inexpensive and easy to administer, and if early detection has been shown to affect outcome positively. Colorectal cancer screening fits these criteria.
- Last year, every Vermont surgeon treating colorectal cancer voluntarily supplied surgical outcome data to support a thorough examination of the relationship between colorectal surgical volume and patient outcome. The data revealed that the most distinguishing factor regarding patient outcome was not surgical volume, but the disease stage at which patients presented for treatment. These findings further underscore the importance of early detection of colorectal cancer.
- Funding for cancer research should be based on the quality of the study design, not on the popularity of the disease. Research conducted on some of the rare and less common cancers has proven highly beneficial to the understanding and treatment of many other cancers.

NEW HAMPSHIRE

Presenters:

Ms. Martha Wells
Dr. Marguerite Stevens
Ms. Arlene Munn
Dr. Denis Hammond
Ms. Laurie Rosa

MS. MARTHA WELLS

Background

The New Hampshire Health Department's Division of Disease Prevention houses its tobacco prevention program, oversees Healthy New Hampshire 2010 objectives, and administers the Five-A-Day program, the Choose Your Cover campaign, and New Hampshire Celebrates Wellness, a community-based health promotion program. Vermont and NECON shared their experience in support of the first Healthy New Hampshire initiative.

The New Hampshire breast and cervical cancer screening program and the cancer registry are administered by the Office of Community and Public Health and are located at and supported by a contract with the Norris Cotton Cancer Center. The Department has nearly completed the planning phase of the Healthy New Hampshire 2010 initiative; public hearings are underway to receive comments on the draft document.

For several years, New Hampshire has had a broad-based Tobacco Prevention Task Force consisting of 25 agencies that developed a comprehensive tobacco prevention and control plan reflecting CDC's criteria for a comprehensive tobacco control program. As a result of this plan, the Department obtained \$3 million in tobacco settlement funds for tobacco prevention and control. This was particularly noteworthy

given that the award came at a time during which funding for education was badly needed. Last week, the State released a report on the first Youth Tobacco Survey performed in New Hampshire. Initial survey participants included seventh and eighth graders; sixth graders and high school students will be surveyed in the spring.

Over the past 4 years, more than 3,000 (out of 9,000) eligible women have been screened through New Hampshire's breast and cervical cancer screening program. Of the 3,000 women screened, 28 cases of cancer have been identified and all women who wished to be treated have received treatment. The State Medicaid plan and budget have incorporated a Medicaid waiver (currently under Congressional review) that would allow these women to continue receiving treatment through Medicaid.

For a relatively small State, New Hampshire is fortunate to have a considerable amount of health care resources. There are 57 mammography units, and radiology/oncology is available in five locations statewide. The State is challenged to ensure that people are able to access these resources. A chronic disease epidemiologist has recently been added to the Department who will develop a comprehensive cancer control plan to be used to seek additional funding.

DR. MARGUERITE STEVENS

Key Points

- The working poor do not have adequate access to health care in New Hampshire. They do not qualify for Medicaid and may not be old enough for Medicare. They are loggers, carpenters, waitresses, and people working in small businesses that do not provide health insurance. They do not receive preventive services, and do not qualify for CDC-funded breast and cervical cancer screening. Typically, cancer in this population is diagnosed when an individual presents in the emergency room in pain; he or she may well have driven more than 200 miles to reach the hospital.
- The immigrant population in New Hampshire is increasing 100 percent per year in the southern portion of the State and poses new challenges to the health care system. Three community health centers (CHCs) in southern New Hampshire provide care for this population, which consists largely of immigrants from the Balkans, Asia, and Africa who had little or no health care, particularly preventive care, in their native countries. Typically, their initial contact with the CHC is to obtain an initial screening to qualify for social services. It is during this initial screening that physicians are diagnosing people with stage 3 and 4 cancers. Although the immigrant population in New Hampshire is considerably smaller than in other parts of the country, advanced cancer among immigrants is a national disaster that must be addressed.
- Patients are basing their treatment choice decisions largely on economic considerations rather than what is best for their health. Patients want to know what the treatment will cost; they are concerned about leaving behind debts that an elderly wife or working children or grandchildren will have to repay. They want to know how far they have to travel for care and how often they will need treatment. If they are insured, patients can not assume that their insurer will pay for an overnight hospital stay in connection with their treatment, so travel demands and costs must be factored into their decisionmaking about whether or not to seek treatment. Travel costs include the cost of fuel, meals, lodging, childcare, and loss of wages. Some may not have a car that is dependable enough to make the many trips to the treatment facility, or they may be unable to afford the gasoline. Inexpensive lodging may be available near the treatment facility, but most cannot afford lodging for the entire family during a lengthy treatment period. Many parents of pediatric cancer patients are unable to pay for lodging and spend the night in the hospital either sitting up in a chair or sleeping in bed with their sick child.

- Childcare often becomes a major problem for cancer patients and their families. If a mother of young children requires cancer treatment, who will care for the children in her absence? If the patient is a grandparent who has been caring for his/her grandchildren, cancer treatment may mean that the working parent must leave his or her job to resume childcare.
- It is not uncommon for the spouse of a cancer patient to lose his or her job as a result of the treatment process. Spouses typically provide transportation to and from treatment and they often are the primary caregivers. In order to serve in this capacity, working spouses frequently use up their vacation, sick time, and unpaid medical leave. Eventually, the employer may become unwilling to accommodate further an employee who is absent so much. If the spouse is terminated from his/her job, the family is often left without either income or health insurance.
- As co-investigator in The Support Study, a study of patients with advanced lung and colorectal cancer, Dr. Stevens noted that 90 percent of the families of study patients used all of their family's savings and depleted most, if not all, of their family's assets to manage the disease of the cancer patient who eventually died.
- The cost of cancer drugs is so high that patients cannot afford to take their medications as prescribed. For example, the antiemetic Zofran costs \$25 per pill and certain patients must take this medication at four hour intervals around the clock. Because of the cost, some patients are enduring treatment without antiemetics and pain medications. Informal pharmaceutical exchanges have emerged whereby patients distribute their unused medications such as tamoxifen to other patients in need. Dr. Stevens found that patients entering the palliative care stage incur approximately \$700 per month in prescription drug costs; many of these patients have no prescription drug coverage and pay for their medications out-of-pocket.
- Reduced hospital stays have resulted in an extraordinary increase in demand for home care, hospice, and nursing home care. Hospitals have significantly improved nursing salaries to retain their nursing staff, but hospice and other community nursing agencies pay the least and are least able to raise salaries to attract and retain nurses. Nurses who previously worked in community-based settings are leaving those jobs to take advantage of the higher salaries offered by hospitals. Three towns in New Hampshire lack sufficient community nursing staff to provide either hospice or home care; this staffing shortage prevents the hospital from discharging certain patients to a more appropriate care setting.
- The trend toward early discharge of patients from inpatient facilities has resulted in patients being discharged with medication pumps, drains, other apparatus, and complicated medication regimens that require relatively advanced nursing care. Home health agencies are so understaffed and unable to attract appropriately skilled nurses that they are forced to hire nurses with insufficient training to attend to these patients.

MS. ARLENE MUNN

Background

In 1995, Frisbie Hospital, a 100-bed community hospital in the coastal area of New Hampshire, conducted a community needs assessment. Two of the four identified health care priorities for the hospital were cancer-related—earlier detection of breast cancer and reducing lung cancer mortality. This community assessment was recently completed for the year 2000; a preliminary review of the data suggests that these priorities remain unchanged due to State cancer trends. The overall cancer mortality rate, and the mortality rate associated with breast and lung cancer are higher in the coastal area than in the State overall. Similarly, the incidence of lung cancer is higher in the coastal area compared with lung cancer incidence in the State. Maternal smoking rates also are considerably higher in the coastal region.

Key Points

- Lack of primary care physicians is a major barrier to health care in Frisbee Hospital's primary service area, and the hospital is actively recruiting physicians.
- The uninsured in the hospital's service area often postpone treatment due to inability to pay for services out-of-pocket; many therefore present with more advanced disease that is more costly to treat.
- Strategies are needed to encourage women in the service area who are over 40 years of age to obtain an initial screening mammogram and annual followup mammograms. Both women and their primary physicians require education to improve screening rates. To measure the success of efforts to detect breast cancers at earlier stages, data collection on stage at diagnosis must be improved at area hospitals and imaging centers.
- Lack of ability to pay for health care is a pervasive issue in the State. Some patients need free care, but many others are willing and able to contribute to the cost of their care. Though a number of programs exist in the State that offer free or subsidized care, information about these programs is not widely disseminated. Patients seeking care through these programs often must complete complex paperwork that can prove daunting to those in greatest need of care.
- The Breast Cancer Awareness Program, which provides free mammograms, is designed to encourage women to obtain a baseline mammogram. The hospital absorbs the cost of the mammogram and volunteers transport the patient to and from the mammogram appointment. Upon request, the volunteers also provide support and guidance at the appointment to help overcome patients' fears. Specially trained volunteers assist in forms completion. Outreach to patients and staff at physicians' offices and to the community is accomplished through brochures, posters, and other advertisements. The program theme, "Be Your Own Caretaker," encourages individuals to take charge of their health, to understand that silence and fear are the ultimate risk factors for breast cancer, and to take advantage of a free, lifesaving program.
- The hospital previously offered an on-site smoking cessation program, but attendance was minimal. Local employers were contacted to host work site smoking cessation and education efforts, however, these also were poorly attended. The hospital is still trying to determine how to make these tobacco control efforts more effective.
- Frisbie Hospital also sponsored an educational anti-smoking program entitled "No Butts About It." Targeting sixth graders, it was implemented in the local school system. Of the students who participated, 83.5 percent decided against smoking. Among those who indicated that the program was not a factor in their decisionmaking, many reported that they had already decided firmly against smoking before participating in the program. Survey results indicated that 3.3 percent of the students already considered themselves to be smokers.
- Lack of coordination among treatment providers and the absence of a physician responsible for the patient's overall management are major barriers to high-quality care. Cancer treatment generally results in multiple system complications, requiring the involvement of a number of medical specialties. Without a case manager, the patient is left without guidance to define his or her most vital needs and gain access to appropriate interventions.

Recommendations

- Hospice, palliative care, and pain management must strongly be supported.
- Information about successful local programs must be made more widely available so that successes can be replicated.

DR. DENIS HAMMOND

Key Points

- New Hampshire's population, although predominantly white, includes a number of ethnic and cultural groups including French Canadians, Latinos, Asians, African Americans, Eastern Europeans, and others. Effective communication about medical care and cultural issues with these diverse populations often requires skilled translators who are in short supply.
- In Manchester, New Hampshire, a Catholic and a nonsectarian hospital merged to create a citywide healthcare system, however, the merger failed due to differing moral/ethical views and resulted in a loss of millions of dollars. Many large, excellent cooperative programs that were created have split into small, effete, competing programs. The collapse of the merger has also halted future health planning efforts as money is being spent trying to reconstitute two competing health care systems. This situation is a tragic example of how excellent and rational health care planning was undone by the intolerance of different groups for one another's values and mores.
- Cancer care information (both accurate and inaccurate) is so abundant that many patients become confused. Patient autonomy is important, and patients should be encouraged to become informed about their disease and its treatment. Ultimately, however, patients also must be able to trust their health care providers so that care can proceed.
- Health care policymakers and the public at large have failed to address a number of fundamental questions:
 - Is health care a right or a privilege?
 - Do all Americans have the right to the same level of health care but not to a higher level?
 - If so, how do we set those standards and what are they?
 - If not, how much of our national resources should be devoted to health care?
 - Is prevention more or less important than treatment?
 - How do we divide up prevention and treatment resources?
 - Should people be free to harm themselves either by substance abuse or lifestyle?
 - If so, who will pay for those self-induced disabilities?
 - What constitutes true quality health care, how do we measure it, and is it achievable?
- The Federal Government is responsible for the majority of the resources used to combat cancer. Medicare accounts for 40 percent of adult cancer care expenditures and Medicaid is responsible for an additional 5 percent. The NCI and the Health Care Financing Administration (HCFA) set patient care standards and create the rules governing reimbursement; thus, it is essential that these guidelines are developed thoughtfully and deliberately.
- New Hampshire's catastrophic illness program pays for outpatient medications for patients who cannot afford their medications. It is an excellent program, but its funding is inconsistent, and the fund is frequently depleted.
- Commercial insurance plans account for much of the cancer care funding not supported by public payers. Until recently, commercial plans controlled the costs of new technologies by denying claims, but passage of a clinical trials bill requiring that State-regulated insurers pay for the routine medical care costs associated with clinical trial participation will provide a major impetus for change in

third-party reimbursement practices. Information obtained through clinical research will improve patient care and outcomes that in turn will extend the value of the health care dollar.

- Medical schools, nursing schools, and other institutions that train health care workers clearly contribute to better patient care, but the cost of this training is keeping many young professionals who would like to work in underserved communities or in less highly paid areas of health care (e.g., primary care) from doing so because they are afraid they will not be able to repay student loans or make an adequate living.
- Though it is popular to vilify the pharmaceutical companies, most cancer treatment drugs available today are the result of work and extraordinary expenditure by private pharmaceutical companies. These companies also support professional education and private advocacy groups.

Recommendations

- Many of the rules and regulations that are put in place appear to be arbitrary and pose considerable burdens on health care providers. More emphasis should be placed on education with less effort devoted to punishment and monitoring.
- The clinical trials process must be streamlined and necessary resources must be allocated to answer critical research questions.
- Smoking cessation must become a national goal. Smoking costs \$97 billion per year: \$50 billion in direct health care costs and \$47 billion in lost wages and productivity, according to the CDC. By comparison, the U.S. Public Health Service developed a smoking cessation program that is estimated to cost \$6.9 billion per year. A more robust anti-smoking program should be established.

MS. LAURIE ROSA

Key Points

- In 2000, 32 million people in the U.S. were aged 65 and older. Over the next 25 years, this population will increase to 51 million people, or approximately 17 percent of the total U.S. population. It is well documented that the risk of developing cancer is ten times greater in people over the age of 65 compared with those 64 years of age and younger. The demand for hands-on nursing care can be expected to increase in proportion to the aging of the population, yet the supply of well trained baccalaureate-level nurses is dwindling. In the past year alone, enrollment in baccalaureate nursing programs declined 5 percent.
- The average practicing nurse today is 45 to 46 years old; less than 10 percent of the nursing population is under the age of 30. These statistics indicate that fewer nurses will be available to care for an increasing volume of elderly cancer patients. The acute nursing shortage is anticipated to peak by the year 2010 as the current supply of nurses begins to retire. By the year 2020, the Nation will have 20 percent fewer nurses than it needs.
- In addition to providing patient care, nurses serve a vital role in education and advocacy. Nurses often act as guides, navigating patients through the complexities of the health care system. They teach patients and families about their diseases, explain complex treatments, describe side effects management, decipher Internet information and advise on making healthy lifestyle changes. Empowering a person with knowledge and hope creates strength. Nurses inspire patients to seek out their strengths. The United States should examine the role nurses play in providing quality health care.
- Fear poses a significant barrier to quality care and must be taken into account when developing prevention and early detection models. Cancer-related statistics more often inspire fear than motivate

people to adopt healthy cancer prevention and screening practices. A woman who views yearly mammograms as a “hunt for cancer” will be less likely to seek this valuable screening tool. Approaching a mammogram as a healthy habit to adopt may result in better compliance. Examining what motivates health practices and how fear can impact a person’s decisions to forego screening may lead to new approaches to prevention.

DISCUSSION—STATE OF NEW HAMPSHIRE

Key Points

- When we compare the U.S. health care system to the health systems that exist in other countries, we tend to focus on the significant number of uninsured and underinsured in the U.S. versus in other countries. However, people who live in countries with universal access to health care do not necessarily have access to cancer care. Countries with national health insurance struggle with the same issues of resource allocation and people do not necessarily receive all of the health care that they need or perceive they need.
- Dr. Hammond noted that he received a Robert Wood Johnson Foundation grant in conjunction with the Norris Cotton Cancer Center to examine the role of nurses in delivery of cancer care. One of the nurses in the practice serves in a variety of capacities but principally is considered to be an ombudsman for patients receiving palliative care. It has been said that the fatal event is birth; after that we all are dying and what matters is how we spend our time. Enriching that time is part of providing good medical care, but it is a task at which the medical model fails badly. Nursing, by contrast, is devoted to enriching the patient’s time.
- In the breast cancer screening program sponsored by Frisbee Hospital, women who are diagnosed with a suspicious lesion following their first mammogram are referred to a primary care physician and a member of the hospital’s oncology department is notified to provide patient followup. Patients who are eligible for the free screening program also can receive free treatment at the hospital. No patient is turned away. The hospital absorbs the costs for eligible patients and supplemental funds are provided through donations. A similar pattern of free treatment exists in all New Hampshire hospitals. This free care does not, however, include outpatient medications, reconstructive surgery, or complementary services or therapies.
- Under the current system in New Hampshire, patient care costs that exceed Medicare or Medicaid reimbursement are absorbed by the State.
- New Hampshire has one of the lowest managed care penetration rates of any State in the country. For this reason, most people in New Hampshire have not had the types of adverse experiences recounted by other panel participants. Dr. Hammond indicated, however, that there have been conflicts between health care providers and managed care program medical directors that culminated in litigation. Ultimately, most patients have received the care they needed, but not without considerable aggravation and expense.
- Medicaid in New Hampshire has very stringent eligibility criteria, requiring patients and their families to divest themselves of virtually all assets in order to qualify for coverage.
- It is particularly difficult to assess the actual experience of patients who have been turned away from the health care system, only to return when their disease is at an advanced stage and the chance for a positive outcome is compromised.
- While the working poor in New Hampshire do receive treatment for their cancer, they tend to enter the system late and the treatment options they select may depend more on convenience and cost rather than on what is best medically.

- While specific centers and oncology practices in New Hampshire have policies in place to ensure access to cancer for the uninsured and others unable to pay, the health department in New Hampshire has not previously assessed the cancer care access of the population as a whole.
- Vermont, New Hampshire, and Maine have either exclusively not-for-profit hospitals, or a preponderance of such hospitals in the State. The not-for-profit structure may provide more flexibility than is found in for-profit institutions to provide free or subsidized cancer care.
- Ms. Anderson, representing the Yale Cancer Center, indicated that the situation in Connecticut with respect to providing free or subsidized cancer care was virtually identical to what has been described in other parts of New England, however, it has changed considerably with the rise of managed care in Connecticut. Physicians now feel pressured to conform to managed care practice standards whereas they had been accustomed to providing care based solely upon their independent medical assessment.
- No one in the United States should have to rely on charity care to see that his or her health care needs are addressed. The current systems of charity care may be in decline, but the goal is not to restore charity care. Instead, we need to develop a health care system that ensures that everyone, regardless of ability to pay, receives the same level of care.

CLOSING REMARKS—DR. HAROLD FREEMAN

Dr. Freeman highlighted the day's testimony and thanked the speakers for their participation and for providing valuable insight into the serious problems that people encounter in seeking cancer information and cancer care.

I certify that this summary of the President's Cancer Panel meeting, *Improving Cancer Care For All: Real People—Real Problems; Why Don't All Americans Get The Best Available Cancer Care?*, held September 14–15, 2000 is accurate and complete.

Certified by: Harold P. Freeman Date: 1/22/03
Harold P. Freeman, M.D.
Chair
President's Cancer Panel