

MEETING SUMMARY PRESIDENT'S CANCER PANEL

LIVING BEYOND CANCER: MEETING THE CHALLENGES OF ADULT SURVIVORS

November 4, 2003
Birmingham, AL

OVERVIEW

The purpose of the meeting was to examine adult survivors' challenges in living after diagnosis and treatment of cancer, including access to long-term care, obtaining and maintaining employment, and a variety of economic and social issues. The President's Cancer Panel (PCP, the Panel) is seeking input to help develop its recommendations to the President of the United States, the U.S. Congress, the Secretary of Health and Human Services (HHS), and the broader community of researchers, policy makers, advocates, and others.

PARTICIPANTS

President's Cancer Panel

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

National Cancer Institute

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, President's Cancer Panel
Julia Rowland, Ph.D., Director, Office of Cancer Survivorship

National Coalition for Cancer Survivorship

Debra Thaler-DeMers, R.N., O.C.N., P.H.N.

Speakers

Mr. Matthew Brewster, Community Representative, Alabaster, Alabama
Ms. Alisa Gilbert, Community Representative, Anchorage, Alaska
Mr. Emanuel Hamelburg, Community Representative, Stoughton, Massachusetts
Dr. Alexander Hantel, Member, ASCO Breast Cancer Surveillance Expert Panel, Naperville, Illinois
Ms. Judy Lundgren, President, Oncology Nursing Society, North Arlington, Texas
Dr. Glen Mays, Senior Health Researcher, Mathematica Policy Research Center for Studying Health System Change, Washington, District of Columbia
Dr. Shelby Sanford, Radiation Oncologist and CEO, Southeast Cancer Network, Tuscaloosa, Alabama
Ms. Susan Shinagawa, Community Representative, Spring Valley, California
Mr. Tom Trotter, Community Representative, San Diego, California
Dr. Christopher Turner, Oncologist, Dana-Farber Cancer Institute, Boston, Massachusetts
Ms. Barbara Young, Community Representative, West, Mississippi
Dr. Boonsee Yu, Community Representative, East Northport, New York

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

On behalf of the PCP, Dr. Leffall welcomed invited participants and the public. He also provided a brief overview of the history and purpose of the Panel and the aims of the current series of meetings on survivorship. Dr. Leffall explained that this meeting would include testimony on the experiences of adult cancer survivors and their families and caregivers, as well as testimony from representatives of the provider and insurer communities.

Dr. Leffall introduced Dr. Julia Rowland, Director of the NCI's Office of Cancer Survivorship (OCS), who spoke on behalf of Dr. Andrew C. von Eschenbach, Director of the NCI.

NCI DIRECTOR'S REPORT— DR. JULIA ROWLAND

Key Points

- Dr. Rowland conveyed Dr. von Eschenbach's regrets at not being able to attend the meeting. She noted that this series of meetings would not have been possible 30 years ago. The concept of cancer survivorship did not exist at that time, and the word *cancer* was seldom spoken. Many cultures around the world are not yet as open as the United States in discussing cancer. The language of survivorship began in the early 1980s with the experiences of a young physician, Fitzhugh Mullan, who diagnosed his own testicular cancer and wrote an article, published in the *New England Journal of Medicine*, about what he called "the seasons of survivorship."
- As the cancer community enters a new millennium armed with new knowledge about the human genome, there are almost ten million cancer survivors, compared to three million in 1971, when the "War on Cancer" was launched. The majority of people diagnosed with cancer today can expect to be long-term survivors. However, survivorship comes with a cost. Cancer affects not only organs and other body parts, but it affects people and their families. The effects can be physical, social, emotional, cognitive, spiritual, and economic.
- Awareness of the importance of addressing these effects of cancer as part of the NCI's scientific mission led to the establishment of the OCS in 1996. The most important stimulus in creating the OCS was advocacy from the survivorship community. Ellen Stovall, currently Chief Executive Officer of the National Coalition for Cancer Survivorship (NCCS), told the NCI Director that it was not enough to enable people to outlive their diagnoses; it was necessary to learn what kind of life cancer survivors were returning to. The OCS is mandated to promote and direct research to address issues related to the quality of life and length of survival of those diagnosed with cancer.
- In 1999, when Dr. Rowland was appointed Director of the OCS, the NCI supported approximately 24 grants focusing on post-treatment outcomes. Today, there are almost 90 grants in that area, and a recent Request for Applications (RFA) on long-term survivorship resulted in the submission of 125 applications. The cancer research and health provider communities are beginning to recognize that survivorship is a critical part of comprehensive care. Awareness of issues related to survivorship has also been a factor in shaping Dr. von Eschenbach's Director's Challenge goal to eliminate the suffering and death due to cancer by 2015. The OCS will play an important role in helping reach that goal.
- Current knowledge has already made it possible to tailor treatment to the needs of individual patients. For example, Lance Armstrong was fortunate enough to be treated by compassionate physicians who

tailored his treatment in a way that protected his lung capacity, enabling him to continue his cycling career.

- In 2002, Dr. von Eschenbach became the first cancer survivor to serve as Director of the NCI. He understands the needs and concerns of cancer survivors and their families. Dr. Rowland stated that the testimony from this series of Panel meetings on survivorship will be heard and acted upon by the NCI.

SURVIVORSHIP CHALLENGES FOR ADULT SURVIVORS: AN OVERVIEW— MS. DEBRA THALER-DeMERS

Background

Ms. Thaler-DeMers, a two-time cancer survivor, is the President of Cancer ACCESS, an advocacy and counseling organization for people affected by cancer, and a member of the Board of Directors of the NCCS. She has worked as an oncology nurse for over a decade and is particularly interested in the long-term effects of cancer treatment and quality-of-life issues for cancer survivors.

Key Points

- Survivorship is not a static state. It begins with diagnosis and includes several phases. The acute phase encompasses treatment; in the extended phase, survivors may experience remission or chronic disease; the permanent phase brings cure or long-term survival; and the final phase represents death, from either cancer or another cause.
- In the acute phase of survivorship, access to high-quality medical care is a central concern. This access is primarily determined by whether patients have employer-provided insurance benefits. High unemployment rates and reductions in employer-provided benefits are increasing the number of uninsured and underinsured Americans.
- Geographic barriers also affect access to care. The burden of treatment for residents of rural areas is compounded by the costs of travel and temporary housing. The ability of patients to obtain treatment near their homes is threatened by proposed changes in Medicare coverage for chemotherapy drugs that may force oncologists to stop treating patients in their offices.
- Few adult cancer patients and survivors enroll in clinical trials. This is primarily a reflection of the public's lack of knowledge and understanding about clinical research. A mass media campaign is needed to promote a better understanding of the benefits of participation in clinical trials.
- Ms. Thaler-DeMers was part of a multidisciplinary team that developed the *Cancer Survival Toolbox: Building Skills That Work for You*, a self-learning audio program designed to help survivors and their families develop practical daily-life tools to deal with cancer diagnosis and treatment. The *Toolbox* includes a module on the needs of older adults, and a survivorship module is being developed.
- Health care providers should be able to nonjudgmentally discuss long-term survivorship issues, such as the effects of treatment on sexuality and fertility. Patients are focused on their treatment and are not aware of the likelihood of long-term effects unless their doctors inform them. However, communication skills are not being taught in medical schools. Physicians are also poorly prepared to help patients deal with end-of-life issues.
- Survivors need skills not only in finding information, but also in evaluating it. Much of the available information is not accurate. The ability to evaluate and comprehend information can be limited by

language barriers, technical terminology, and cultural issues. Health Insurance Portability and Accountability Act (HIPAA) regulations also sometimes hinder efforts to treat patients as part of a family unit.

- Before making decisions about their care, patients need to understand all of their options, including complementary or alternative treatments and adjuvant or neoadjuvant options. If a doctor presents a patient with only one option, especially when it is presented as a life-or-death choice, the patient is likely to sign a consent form without reading it.
- Cancer patients are faced with numerous situations that test their problem-solving skills. Hospitalization places a serious burden on single parents and on those who must continue to work to maintain insurance coverage. Depression is often a comorbid condition associated with cancer, but most patients are not prepared to deal with this problem, and its treatment is not often included as part of a cancer patient's care.
- Fertility issues should be addressed before treatment begins. Informed consent should not be assumed unless patients have been informed about these issues. Since infertility is often caused by treatment, insurance should pay for treatment of the resulting infertility. In addition, offspring of cancer survivors should be tested for adverse genetic effects of the parent's cancer treatment.
- Survivors need good negotiating skills to deal with workplace, insurance, and long-term care issues. They may have to request workplace accommodations or seek retraining to find less stressful or risky employment. They may also have difficulty obtaining support in areas such as pain management, physical rehabilitation, and psychosocial care.
- Although it is well known that cancer treatment can cause new cancers to appear years later, as well as other long-term health problems, oncologists follow patients for only a few years after treatment, and primary care physicians are not educated about late effects of treatment.
- Late-effects clinics should be created for adult cancer survivors. An effective first step toward this goal would be to require comprehensive cancer centers to establish such clinics. Insurers should be provided with incentives to support long-term care. A national education campaign to inform survivors about the types of monitoring they need should be initiated by the NCI.
- A comprehensive national cancer insurance plan should be established, and everyone diagnosed with cancer should immediately be enrolled in that plan. This plan would ensure access to comprehensive, multidisciplinary cancer care; increase enrollment in clinical trials; promote routine screening and prevention; and mandate long-term follow-up care.
- Most cancer providers do not provide psychosocial care because they are not reimbursed for these services. With the advent of managed care, oncology social workers were eliminated or redirected to perform discharge planning instead of counseling, making it even more difficult for patients to find counseling.
- An impartial study should be conducted to accurately determine the costs of comprehensive care, including psychosocial care, and Medicare reimbursement rates should be adjusted to support all aspects of comprehensive care.
- In spite of the Americans With Disabilities Act, employment discrimination is still a problem for cancer survivors. Discrimination based on a cancer diagnosis is difficult and expensive to prove. Statutes against discrimination need better enforcement, and employer incentives should be created to encourage the hiring of cancer survivors.

- A “safety net” program should be created to protect basic assets of cancer patients and survivors. An illness should not cause financial ruin for families.

DISCUSSION—MS. THALER-DeMERS

- Although universal medical coverage would be desirable, it is not politically realistic to expect it to be implemented soon. However, cancer affects such a large number of American families, it is more realistic to envision a universal insurance plan for those diagnosed with cancer. Universal Medicare coverage for dialysis, which protects Americans with renal failure from bankruptcy, could serve as a precedent for providing similar protection to cancer patients.
- The Centers for Disease Control and Prevention (CDC) has funding for educational programs and should be included as a major component of any NCI-led public education campaign.
- Cancer survivors have many opportunities to become involved in addressing these issues: participation in NCCS activities; volunteer work in support of the NCI’s consumer-related programs; and independent political advocacy on issues such as Medicare reimbursement for chemotherapy.
- In providing patients with information about the effects of treatment, caregivers need to be aware of the best “teachable moments” for offering this information. Patients who have just received a cancer diagnosis may not hear everything that is said afterward, so information needs to be repeated, and certain procedures should not be conducted until the patient’s understanding of relevant issues has been confirmed.
- Cancer centers find it difficult to conduct long-term follow-up of patients who consider their treatment to be finished and do not provide forwarding information should they move. The best solution to this problem is educating survivors about the need for follow-up. Provision of this kind of education should be a criterion for designation as an NCI Comprehensive Cancer Center.
- Satellite centers affiliated with comprehensive cancer centers but located within the community, especially in rural areas, should be established to provide long-term follow-up.
- When patients are informed about HIPAA regulations, they should be given an opportunity to list family members and others to whom information about their care can be provided.
- Many cancer survivors erroneously believe that problems with sexuality are an inevitable side effect of treatment and that they must accept this situation. Physicians and other health care providers should be taught that this is a common problem and be provided with the communication skills to help survivors overcome these problems.
- Many people avoid clinical trials because they fear they may receive a placebo instead of actual treatment. The public needs to be told that trials usually compare one treatment approach with another, that patients who do not respond to experimental treatments are returned to standard treatments, and that no harm is done or treatment denied to those who participate.
- The recent Tour of Hope, organized by the Lance Armstrong Foundation and Bristol-Myers Squibb, is an excellent example of a program to raise awareness of clinical trials for adult cancer patients.
- When the Alabama Comprehensive Cancer Plan was written in 2001 in response to a CDC RFA, survivorship was addressed in a limited way within the section on treatment. The Alabama Department of Public Health is in the process of revising its cancer plan to include a separate and more comprehensive section on survivorship.

- The NCI's *Facing Forward: Life After Cancer Treatment* patient education publication is a good source of information on major national organizations that deal with survivorship issues.
- Many of the cancer survivors who are involved in advocacy and education are motivated by the "obligation of the cured," a phrase coined by Lance Armstrong expressing commitment to help others in the same situation.
- The NCI's partnership with the CDC reflects an increasing emphasis on addressing cancer as a chronic disease. Together, they can help local agencies revise their cancer plans to address survivorship issues. The CDC and NCI can provide states and communities with tools to help them select targets that they can realistically meet.

STORIES FROM SURVIVORS—GROUP I

Presenters

Mr. Matthew Bennett

Ms. Alisa Gilbert

Ms. Susan Shinagawa

MR. MATTHEW BENNET

Background

Matthew, a 38-year-old married father of two, was diagnosed with testicular cancer at the age of 30. His cancer, misdiagnosed as seminoma, was treated with surgery and radiation, and he was told that his back pain was normal. When he later experienced severe back pain, he was referred for a second opinion to an oncologist in Indiana who told him that his cancer, now identified as nonseminoma, had recurred. He was given chemotherapy to treat the nonseminoma, as well as surgery to remove cancerous nodes in his abdomen.

Key Points

- Matthew feels that survival is a journey—not necessarily a destination, but a new way of life.
- Matthew lost his job due to excessive time off during his first treatment. He relocated for a new job, and his new employer's support, along with the support of his wife's employer, was instrumental in the success of his second treatment. Matthew and his wife were secure in the fact that they were not going to lose their jobs while Matthew underwent treatment in another state, and that security made a difference.
- As cancer treatment advances, the need for long-term survival support increases. When Matthew reached his five-year survival anniversary, he felt lost, not knowing what he was supposed to do from that point, emotionally or medically. An oncology counselor assured him that his depression was a part of the long-term process and that he was still responsible for finding follow-up protocols wherever he could.
- Issues surrounding health, life, and disability insurance coverage are some of the biggest long-term obstacles for Matthew. Large insurance companies tried to use fear tactics to sell low-dollar coverage at extremely high prices, denying him standard coverage even after his doctors told him he was statistically no more likely to develop cancer again than anyone else. Michael was also denied

disability coverage based on his survivorship status, which leaves his family open to financial ruin should something happen to him—even if it is not cancer-related.

- Matthew believes there should be an extensive Internet-based program to provide ongoing education and support on demand to long-term survivors. It should be the definitive source for information for long-term survivors, newly diagnosed patients, health care community members, and others who want to get involved.

MS. ALISA GILBERT

Background

Alisa, a 41-year-old Native American cancer survivor, was diagnosed with breast cancer at age 31. She received high-dose chemotherapy and a double mastectomy. Following her last chemotherapy treatment, more tissue was removed, and her doctors performed reconstruction surgery. In 2000, Alisa started her own organization to help cancer survivors: the Office of Native Cancer Survivorship (ONCS). She has set up a toll-free support line and a Web site. Her goal is to help Native cancer patients and survivors find the information they need about late effects of treatment and the impact of cancer on employment, marriage, and quality of life.

Key Points

- Alisa credits her medical team with great treatment, both medical and educational. Her team gave her the education that empowered her to educate other Native survivors.
- Cancer survivorship is not yet a common concept in the Native culture. For Native Americans, cancer is something that happens to people, and they get through it and then get back to their lives as best they can, but they do not relate to the term *survivor*. Alisa believes this is changing; through her work with ONCS, she has become convinced that Native survivors do want to connect with other people.
- At the time of her diagnosis and treatment, Alisa was a Medicaid and Indian Health Service (IHS) beneficiary, and she did not have private health insurance. Her cancer was financially devastating, forcing her to beg and borrow in order to cover basic expenses. She chose to stay in Seattle instead of going back to the reservation and gaining coverage under the IHS system. After her surgery, Alisa developed a staph infection; her doctors had not included necessary drains because she was a Medicaid patient, and the infection required many additional therapies and outpatient visits to have her chest drained. She was denied coverage for her implants and nipple areola surgery as well. Alisa credits her plastic surgeon with insisting upon the surgery and advocating on her behalf.
- Alisa worries about the side effects of treatment. As a result of her high-dose chemotherapy, she went into early menopause. The temporary menopause has since reversed, and she has two children.
- A comprehensive survivorship plan for each cancer patient should be advocated by the Panel. Survivors must take an active role in their care and define their long-term needs. Patient-doctor communication is important, as is keeping up with treatment advances.
- Connecting with other survivors has enriched Alisa's life. Helping others navigate cancer and survivorship has helped in her own healing process. She believes that she has the ability to make a difference in long-term survivorship and improve the survival rate for Native patients, which is currently the lowest in the country. Alisa urged people to get involved in the national cancer movement.

- The Navigating the Health Care System for Alaska Native Cancer Patients program has been an incredible help in addressing the issue of travel for cancer patients.
- The ONCS is implementing an education and awareness campaign that will specifically target survivorship issues. The ONCS Web site also offers support, regardless of how remote the user's location.

MS. SUSAN SHINAGAWA

Background

Susan was first diagnosed with breast cancer in 1991. She experienced a recurrence in 1997 that affected her spine, and she developed a secondary breast cancer in 2001. She is disabled by severe, chronic pain for which she is being treated with a variety of medications, including opioids delivered through implanted drug-delivery devices. After years of resisting psychological interventions, Susan is now being treated for clinical depression through psychotherapy, medication, and complementary stress-reduction programs. Although her activities have been curtailed by disability, Susan has long been active in advocacy work, including serving as Chair of the Intercultural Cancer Council from 1999 to 2001.

Key Points

- There is a paucity of evidence-based survivorship research, particularly regarding communities of color and poverty, and the body of work looking at Asians/Pacific Islanders is meager.
- The National Coalition for Cancer Survivorship defines cancer survivorship as beginning at the moment of diagnosis and continuing for the remainder of life, but this concept is not necessarily culturally relevant to Asian cancer patients, many of whom believe that cancer is punishment for past transgressions or for whom stoicism is culturally ingrained. For Asians and other ethnic and cultural minorities, the definition of pain and how one deals with it is as much a part of one's culture as it is a matter of physical perceptions.
- The most difficult aspect of Susan's cancer experience has been dealing with the medical system. She encountered misinformation and resistance from the medical community, including nurses who dismissed her breast lump because they believed that breast cancer did not hurt; a surgeon who refused to biopsy her lump because, in his opinion, she was too young to have breast cancer, she had no family history of cancer, and Asian women did not get breast cancer; a medical oncologist who made an entry in her medical chart indicating that Susan needed psychiatric counseling because, after he told her he did not have time to answer her questions, she demanded that he address them and would not let him leave until he did; a hospital that continued to bill her for four years after she finished chemotherapy for charges her insurance company would not pay; and an insurance company that charged a \$550 monthly premium but would not pay for her breast prosthesis because it exceeded the covered amount by \$70.
- Susan continues to experience long-term and late effects from her cancer and its treatment. She suffers from physical effects, such as urinary retention, constipation, hot flashes, headaches, intermittent nausea, vomiting, and sleeplessness; mental effects, such as lags in thought processes, lags between actions and reactions, slowed cognitive abilities, diminished vocabulary, impaired recall, and severely impaired short-term memory; and emotional effects, such as depression and feelings of isolation. Susan is no longer able to take part in the outside activities she once enjoyed, nor can she drive or enjoy a healthy sex life with her husband.

- Asians/Pacific Islanders, especially recent immigrants, are unfamiliar with the mainstream Western health care system—a problem compounded by language barriers—and often seek treatment from practitioners of traditional medicine or cultural healers. The common practices of cupping or coining are believed to help rebalance the *yin* and *yang*; an imbalance is the traditional Asian concept of illness. However, these practices often leave bruising on the patient’s body. To avoid embarrassing questions from health care providers and the suspicion of law enforcement officers that parents have abused their children, many patients will avoid going to a clinic or hospital if traditional healing is unsuccessful.
- Lack of understanding of Western health care concepts and practices highly impacts the health seeking behaviors of Asians/Pacific Islanders. The health care community needs funding to train culturally competent pain management specialists who can educate other medical providers about pain. Funding is also needed to conduct research in several important areas: pain pathways and treating pain effectively; institutional, cultural, and individual barriers that preclude appropriate and timely pain management for people of color and those living in poverty; and culturally relevant interventions to overcome those barriers.

DISCUSSION— SURVIVOR GROUP I

Key Points—MR. BENNETT, MS. GILBERT, MS. SHINAGAWA

- In response to a question from Dr. Leffall, Ms. Gilbert further described the Navigating the Health Care System for Alaska Native Cancer Patients program. She believes that the program has helped identify how many channels people go through to get the best care possible, and it has improved communication between doctors, providers, and patients.
- Having a medication pump with a catheter that goes into the intrathecal space in her spine has made a difference in pain management for Ms. Shinagawa. She is not functional every day, but the pump makes it possible for her to be functional much of the time.
- Dr. Yu (from the audience) suggested meditation and T’ai Chi for pain management. She uses these approaches for her own cancer treatment-related pain.
- Ms. Shinagawa will be participating in a mindfulness-based stress reduction study at the University of California at San Diego, conducted in conjunction with Harvard University, that will include meditation, yoga, and T’ai Chi.
- One of the challenges in survivorship research is deciphering how patients are able to identify positive aspects of the experience of having cancer. Researchers want to learn what can be done to enable a survivor to start a new life and be reaffirmed in living that life, rather than succumb to depression.
- Palliative care is moving forward, focusing not only on what to offer terminal patients, but also on symptom control throughout the entire treatment process.
- In a number of Asian communities and cultures, there are no words for *survivor* or *chemotherapy*, and the concept of prevention does not exist.

STORIES FROM SURVIVORS—GROUP II

Presenters

Mr. Emanuel Hamelburg

Mr. Tom Trotter

Ms. Barbara Young

Ms. Boonsee Yu

MR. EMANUEL HAMELBURG

Background

Manny, a 63-year-old cancer survivor, is retired and recently widowed. He was diagnosed with prostate cancer in 1987 and treated with radiation. In July 1992, just a few months short of five years in remission, Manny was diagnosed with metastatic bone cancer. Through the NCI, Manny was treated with an experimental protocol that included hormone therapy combined with chemotherapy. He ended his treatment in 1992 and remains in remission. Manny is a member of the NCI's Consumer Advocates in Research and Related Activities (CARRA) program and the Massachusetts Prostate Cancer Coalition.

Key Points

- Many men are unwilling to discuss prostate cancer and the side effects of the disease and its treatment, including urinary incontinence and impotence. They do not want to sound ungrateful by complaining about effects after having been helped by their doctors. The cultural expectations placed upon men to be strong also get in the way of family inclusion in the treatment process.
- The hormone therapy Manny received created side effects such as urinary incontinence, hot flashes, gynecomastia (enlargement of the male breast), nocturia (waking up many times at night to urinate), obesity, and loss of libido. One of the focuses of Manny's advocacy is to be as open as possible about such issues, which most men do not want to be open about.
- Manny is very unhappy with currently available treatments for prostate cancer and with the lack of consensus in the medical community about which treatment is best. He feels that doctors often are treating prostate cancer more aggressively than necessary rather than tailoring therapy to the individual patient. Although this approach saves some lives, it leaves many men with serious side effects. Research should focus on developing better treatments for cancer and for the side effects of cancer treatment.
- Cancer patients and survivors need to remember that other parts of their bodies need care as well.

MR. TOM TROTTER

Background

In 1991, at the age of 40, Tom had several melanoma spots removed from his face; another was removed in 2000. In 2001, he was diagnosed with stage IV melanoma, which involved lymph nodes and metastasis to his liver.

Key Points

- There is no standard of care for stage IV melanoma: surgery is a delaying rather than curing action, and neither radiation nor chemotherapy is appropriate.
- Tom has participated in two clinical trials but has still experienced a recurrence of his cancer.
- Tom praises the NCI clinical trials Web site but feels that the Search interface could be improved to make it easier to review criteria for participating in trials.
- Tom qualifies for two health care programs: TRICARE, because he is a retired Naval officer, and the VA because he is a veteran. This has been helpful in some circumstances; for example, the VA declared his latest recurrence to be inoperable, but TRICARE did not. Tom feels blessed to be able to access a truly independent second opinion.
- Tom prefers the phrase *living with cancer* to *being a survivor* because he feels that once you have cancer, you never really live without it, particularly because recurrence is always possible for so many types of cancer.
- Tom is encouraged whenever he meets someone at stage IV who is just a little further down the road, and he tries to be encouraging when he meets someone who is not as far down the road as he is.
- The NCI Web site should utilize greater standardization in presenting cancer trial information, with an advanced search engine to make finding trials easier.
- Wherever possible, the FDA approval process should be accelerated.
- There should be greater latitude for compassionate use of experimental drugs for stage IV patients who have no other options.
- The health care system should recognize that religious belief can function as an exceptionally valuable medicine and in some cases can actually prolong life by reducing stress.

MS. BARBARA YOUNG

Background

Barbara was first diagnosed with cancer in her left breast in 1987, at age 33. She was subsequently diagnosed with stomach cancer in 1994 and with cancer in her right breast in 1997. She underwent surgery for all three cancers.

Key Points

- Barbara is from a rural area of Mississippi. When her doctor found a mass in her left breast, Barbara had to obtain treatment in Jackson, Mississippi. Transportation was limited because her family had only one car. When Barbara started chemotherapy in Jackson, her husband left the family, leaving Barbara to care for three young children by herself. The children did what they could to help: her 14-year-old daughter learned to drive so that Barbara could travel to and from her chemotherapy treatments; the children worked odd jobs for gas money; and her young son hid the car in the woods to avoid repossession when they were unable to make payments.
- Barbara's cancer treatment was financially devastating. She was unable to work; her electricity was turned off; her car was almost repossessed; and she was denied food stamps because she owned a

late-model car. Her treatment continued only because an oncologist and a plastic surgeon treated her at no charge, reconstructed her breasts, gave her money, and helped her children.

- Barbara now visits schools and nursing homes to talk about her cancer experience.

DR. BOONSEE YU

Background

Boonsee, a retired obstetrician/gynecologist, was born in Thailand and lives on Long Island with her husband and two sons. She was diagnosed with colon cancer in 2000, at the age of 53. Her treatment included surgery and chemotherapy. She remains cancer-free.

Key Points

- Boonsee chose a small oncology group in her town on Long Island instead of traveling three hours each way to a cancer center in New York City. She knew that this choice could mean lack of access to advanced treatment and new experimental medication.
- Boonsee's life has been radically changed as a result of her cancer experience. She cannot work as she used to. She is weak and has osteoarthritis in her hands, knees, hips, and lumbar spine.
- Often, health insurance policies make it difficult for physicians to use expensive medications. Boonsee feels she has had better treatment than most because of her educational, financial, and medical resources as a doctor, but she still had to fight for every dose of medication. Her insurance coverage requires her go to different facilities for different tests. As a result, none of her specialists know everything that is being done for her; she must tell each doctor what the others are doing. This lack of communication is common for cancer patients.
- Boonsee survived her cancer but cannot pay for necessary post-chemotherapy treatment. Because of her cancer history, she can neither lower her extremely high insurance premium nor change carriers. She is not old enough to qualify for Medicare and makes too much money to qualify for Medicaid. Boonsee cannot afford physical therapy because of the poor coverage offered by her insurance company. She suffers from severe pain that could be alleviated.
- Health insurance companies would save money by providing support for early detection and early treatment.
- Through talking with other cancer patients in various ethnic groups, especially immigrant populations, Boonsee has found that churches and temples are doing a good job in helping Italian, Spanish, Irish, and Mexican Americans with cancer. Likewise, the Chinese Unit of the American Cancer Society in New York provides extensive support, information, and screening help to Chinese and Korean Americans. The Government should encourage these groups.
- The breast cancer rate is 60 percent higher among immigrants in the United States than it is in their native countries. Only 45.5 percent of Asian/Pacific Islander adult women in the United States have had a mammogram or clinical breast exam within the last two years. Asian/Pacific Islander cultures and beliefs are very much involved in this disparity; people are told that cancer is contagious, cancer is punishment, family comes first, and hospitals are for dying people. These populations need education about surviving cancer.

DISCUSSION—SURVIVOR GROUP II

Key Points—Mr. Hamelburg, Mr. Trotter, Ms. Young, Dr. Yu

- Mr. Hamelburg is concerned that available prostate cancer treatments are not very effective; increased research on effective treatments is needed. He believes that impotence rates after surgery are much higher than most people in the medical establishment think. He feels that many people are suffering unnecessarily from side effects of overly aggressive treatment.
- Ms. Young stated that it is important to know what other cancer patients have done that worked for them during and after treatment.
- Dr. Yu recommended increased research focused on complications and side effects of treatment.
- Mr. Trotter applauded the NCI Web site as an information resource.
- It is very difficult to get information on cancer to rural areas because of the lack of Internet access, television, medical insurance coverage, advertising campaigns, and health care in general. Ms. Young's grandmother served as a midwife in an area where there are no obstetricians or gynecologists. Ms. Young gathers information where she can and distributes it to area churches.
- Paul Sanders (from the audience) recommended a new book by Dr. Paul Lang, head urologist at the University of Washington Medical Center, called *Prostate Cancer for Dummies*, which Mr. Sanders feels is very comprehensive and helpful.

TESTIMONY FROM PROVIDERS/INSURERS—GROUP I

Presenters

Dr. Shelby Sanford

Dr. Christopher Turner

Ms. Judy Lundgren

DR. SHELBY SANFORD

Background

Dr. Sanford is a Radiation Oncologist with the Southeast Cancer Network in Tuscaloosa, Alabama. He attributes much of his philosophy toward medicine and community involvement to growing up in a small town. He has always had an interest in providing quality cancer care and has been instrumental in bringing rural oncology networking to Alabama. He received his M.D. from the University of Alabama School of Medicine and completed his residency at the University of Alabama at Birmingham (UAB). While at UAB, he served for one year as an American Cancer Society Clinical Fellow and one year as an Instructor before moving into private practice. Dr. Sanford is a member of the American Medical Association, a Fellow of the American Society for Therapeutic Radiology and Oncology, a past member of the American College of Radiation Oncology Board of Chancellors, and a founding member of the Southern Association for Oncology.

Key Points

- In 1996, Dr. Sanford and seven colleagues invested \$20 million of their own money to build a comprehensive cancer treatment network in rural Alabama. There are now ten freestanding centers

that combine radiation and medical oncology, and no Alabama citizen lives over 60 miles from a cancer treatment facility. Doctors in the network have addressed access problems by traveling to clinics located near the patients. Dr. Sanford, who lives in Tuscaloosa, travels to Jasper and Winfield (both 60 miles from his home) twice a week.

- The network sees more than ten percent of all cancer patients in Alabama; it will treat more than 3,000 new patients this year and see approximately 25,000 follow-up patients. Expenses average over \$40 million a year, and this is the first year the network will realize a profit. The network has been able to succeed financially because all radiation physics data are centralized in Bessemer, Alabama, thus requiring fewer physicists. In addition, the informatics system and management team are centralized to reduce overhead expenses.
- A unique aspect of Dr. Sanford's practice is that radiation oncologists and medical oncologists work side by side on a daily basis, and there is one nurse dually trained in medical oncology and radiation oncology. Many mistakes are made due to ignorance in the oncology community; medical oncologists are sometimes unaware of side effects of radiation oncology, and vice versa. Centralizing the practice has decreased the number of these problems.
- Oncologists need to explain treatment and prognosis in a way that patients understand and be forthright about uncertainties. Oncologists must not betray patients' trust by neglecting them after the treatment phase.
- Reimbursement is a barrier to cancer care, especially if Congress changes reimbursement for radiation oncology or medical oncology to "bundle charges" such that support (e.g., nursing staff) and supply (e.g., intravenous tubing) costs are not covered. Oncology practices have many expenses (mortgages, utility bills, building and land maintenance costs, personnel expenses, etc.), and poor reimbursement hinders business growth and the practice's ability to provide uncovered services that survivors need. Noncoverage (or inadequate coverage) of vital services—including dietitians, social workers, chaplains, psychologists, sexual therapists, and marriage, family, and oncology counselors—is a barrier to survivors' care as well.
- Lack of insurance coverage for expensive support drugs (e.g., Zofran for nausea and Megace for appetite stimulation) is a barrier to enhanced survivorship. Medicaid's coverage for such drugs is limited, and private insurance companies vary. Nonformulary uses of prescription drugs can also preclude reimbursement.
- Access—patients' ability to get to an oncology clinic—is a barrier. Even with multiple rural facilities, patients must still travel back and forth for treatment and follow-up visits. Transportation can be inflexible and expensive, and many cancer patients are elderly and have ill partners.
- Uncertainty about rehabilitation can be a barrier to quality cancer care. Research to answer questions such as when rehabilitation should be offered in the course of treatment—and to whom—has been insufficient. Rehabilitation includes not only physical rehabilitation, but also psychological and psychosexual rehabilitation; inner peace and freedom from fear are exceedingly important in survivorship.
- A vast amount of information is available to cancer survivors, but it is difficult to navigate and seldom user-friendly. Information resources like the Internet need to be refined.
- Paperwork is often time-consuming and onerous for oncology practices—examples include disability forms, drug coverage forms, secondary insurance forms, PET scan forms, legal assistance forms, work excuse forms, and back-to-work release forms.

- The National Comprehensive Cancer Network (NCCN) is developing pathways for uniform ways to diagnose, stage, and treat cancer patients. However, guidance for uniformity of follow-up care is also needed to ensure better care for cancer survivors and to assist oncologists legally by establishing a national standard of care.
- Since most patients are seen in community oncology clinics, data about them are seldom collected. Access to clinical trials must be improved to take advantage of this currently idle data resource.

DR. CHRISTOPHER TURNER

Background

Dr. Turner is a pediatric neuro-oncologist at the Dana-Farber Cancer Institute in Boston, Massachusetts. He received his medical degree in 1994 from the University of Rochester School of Medicine in New York and completed his pediatric residency training in 1997 at Children's National Medical Center in Washington, DC. Dr. Turner completed a three-year fellowship in Pediatric Hematology-Oncology and a one-year fellowship in Pediatric Neuro-Oncology at Duke University Medical Center. He joined the Dana-Farber Cancer Institute in September 2001. In addition to his clinical responsibilities, he is interested in studying and improving outcomes for children with brain tumors.

Key Points

- Pediatric oncology has addressed survivorship issues for some time and can serve as a template for adult survivorship. Research has been ongoing in childhood cancer survivorship—the Childhood Cancer Survivor Study (CCSS) involves 25 institutions and 14,000 childhood cancer survivors diagnosed between 1970 and 1986. A number of studies are now emerging from this data set, which has a normal-sibling control group of 3,500.
- The Children's Oncology Group (COG) is a large pediatrics clinical trials base that supports 238 institutions with 100 active clinical trials. Approximately 5,000 children a year participate in COG trials, and the Group mandates follow-up for survivorship. Approximately 35,000 survivors from COG trials are being observed. In March 2003, COG released an initial version of *Late Effects Screening Guidelines* for pediatric oncology. Although this first version is likely to be revised, the *Guidelines* address the important issues of continuity and standardized care.
- The Institute of Medicine's (IOM) 2003 report, *Childhood Cancer Survivorship: Improving Care and Quality of Life*, provides a useful summary of current research and directions for future research. The report presents a blueprint for an ideal survivorship system, which would include provision of medical services; identification of late effects (or their risk factors); development of a plan for long-term surveillance; coordination of care of multiple subspecialties; amelioration of late effects through rehabilitation; and provision of psychosocial and spiritual care. Since survivorship is a relatively new phenomenon in cancer, such a clinic would educate and train providers—oncologists, psychologists, nurses, etc.—about survivorship issues and how to conduct research on survivorship. The program would also provide support for families and care coordination and case management for transition from pediatric to adult care.
- The Internet is an important resource for childhood cancer survivors. A list of childhood cancer survivors' clinics can be found at <http://www.acor.org/ped-onc/survivors/index.html>.
- Dana-Farber Cancer Institute's two cancer survivorship programs are the most comprehensive tertiary care clinics in New England and house the largest multidisciplinary team. The David B. Perini Quality of Life Clinic has been in operation since 1993 to serve survivors of all childhood

malignancies and has been influential in developing seminal elements of follow-up care. In recognition of the complex needs of childhood brain malignancy survivors, the Stop & Shop Family Pediatric Neuro-Oncology Outcomes Clinic (the Clinic) became a separate entity in January 2003. The Clinic has approximately 500 unique patient visits a year, equally distributed among general and neuro-oncology patients. The Dana-Farber program also conducts primary cancer survivorship research.

- Treatment for brain tumors is established, including surgery, radiation, and chemotherapy. Nonetheless patients' outcomes vary considerably due to tumor location; outcomes range from difficulties in normal cognitive functioning to significant impairment. Therefore, follow-up systems must account for the wide range of patient outcomes and the particular follow-up needs of individual patients.
- A large, multidisciplinary network of staff is necessary to provide effective follow-up care for patients. Many medical specialties and ancillary services are necessary for the Clinic's success, including neurosurgery, radiation oncology, oncology, neurology, neuroradiology, neuropathology, endocrinology, psychology/social work, neuropsychology, school liaison, psychiatry, physical therapy, occupational therapy, nutrition, resource specialists, reproductive endocrinology, genetics, integrated therapies, ophthalmology, and audiology. Many survivors of childhood cancer are over 21 years of age; therefore, adult follow-up service providers are also necessary, including fertility specialists, adult endocrinologists, and obstetrician/gynecologists. Patient feedback is essential and can reveal important gaps in follow-up services. Whenever possible, primary community oncologists provide the follow-up care that the tertiary care clinic recommends. The Clinic provides patients and their primary care physicians with a medical history card with treatments received and recommendations for follow-up care.
- One of the key objectives of tertiary care clinics is to address survivorship issues at the time of treatment by selecting interventions and treatment strategies that minimize late effects. The Clinic delivers chemotherapy into the spinal fluid and uses innovative treatment strategies such as proton radiation and functional MRI technology to reduce the side effects of initial treatments.
- Educating and counseling survivors regarding the risk of late effects is essential—both at time of diagnosis and after treatment. Lack of medical insurance in young adult survivors who are no longer covered under their parents' insurance plan is also a problem. Education efforts can help survivors realize their need for medical insurance to pay for needed follow-up care. Providers also should be educated regarding consequences of treatment.
- Providers can advocate for survivors by assisting them in accessing resources and lobbying on the national and state levels to improve resources available to them.

MS. JUDY LUNDGREN

Background

Ms. Lundgren, President of the Oncology Nursing Society (ONS) and an oncology nurse with Texas Oncology, P.A., in North Arlington, Texas, has over 21 years of experience in Medical Oncology Nursing. She received her Master of Science in Nursing degree from the University of Texas at Arlington. Ms. Lundgren has served on the ONS Government Relations Committee, as the State Health Policy Health Liaison for Texas, on the Steering Council, and as a member of the ONS Board of Directors and the ONS Foundation Board of Trustees. She has served on the American Cancer Society's Board of Directors, Pain Task Force, and Nurses' Committee, co-chaired the Nurses' Committee, and acted as a support group facilitator for the Man to Man, Dialogue, and Life After Loss programs and the Lymphedema Support Group. She is also a support group facilitator for the Leukemia and Lymphoma Society's North Texas Chapter. From 1996 to 1997, when Ms. Lundgren was Co-Chair of the Fort Worth Tobacco-Free Coalition, she helped pass a strong ordinance prohibiting smoking in the workplace and limiting youth access to tobacco products.

Key Points

- A cancer diagnosis affects not only patients, but also their loved ones.
- Patients have identified several issues that emerge during cancer care and survivorship. The first is employment—patients remain in undesirable jobs for fear of losing medical insurance for themselves and their families. Insurance is another issue—providers often partner with patients to decipher current insurance guidelines and ensure that treatment is covered.
- Advocacy is essential; patients' families and caregivers should become involved in the political process to improve policies and resources available for cancer patients and survivors. For example, disability policies present a real barrier to cancer care. In Texas, persons on disability receive Medicaid for the first 6 months and then have no insurance for another 18 months. Thus, patients have only the first 6 months of their treatment paid, and providers are put in a difficult position. Even when providers are willing to donate professional time, hospital costs, diagnostic tests, and drugs remain uncovered.
- Chronic pain is an issue for cancer patients and survivors, and pain control medication is often inadequate due to a number of factors, including cultural attitudes related to pain medication and addiction, lack of understanding/education on the part of primary care physicians regarding pain control, and patients' lack of knowledge concerning pain-relief options.
- Specific guidelines for long-term follow-up are lacking, and therefore, standards of care are undefined. Data need to be gathered to inform development of guidelines; resulting guidelines should be posted on the Internet and reviewed annually or biannually.
- Fragmentation of care is an issue in survivorship. Survivors are usually under the care of a primary care physician, a medical oncologist, a surgical oncologist, a radiation oncologist, an internist, and possibly a neurologist and pulmonary physician. Streamlining and centralizing a patient's medical information is very difficult, especially under new HIPAA privacy regulations. This problem is particularly difficult for adult survivors of childhood cancers, who often do not keep their treatment records.

- Communication is essential to cancer care and can be the most difficult aspect of practicing oncology. Providers need to communicate in a way that patients understand, and patients should be seen as partners in their own care.

DISCUSSION— PROVIDER/INSURER GROUP I

Key Points

- Information delivery must be tailored to patients' needs, both in terms of access and comprehensibility. Printed information might be more accessible to rural patients than information on the Internet.
- The Internet is a valuable tool for dissemination of information to patients, but care must be taken to ensure that the information is safe, reliable, and peer-reviewed. Duplication of effort often occurs in information dissemination. Patrolled chat rooms, where experienced practitioners screen postings to find questions they can answer, would help prevent “reinventing the wheel.”
- Regional meetings, up-to-date printed materials in cancer centers, and multi-access online exchanges are important means of maintaining providers' access to information and promoting information exchange.
- Patients, providers, and especially members of professional organizations should continue to lobby on the state and national levels for legislative answers to such barriers as reimbursement and access to survivorship services and resources. It is also important to educate the media about issues related to survivorship.
- The Cancer Information Service (CIS) provides free information services through its toll-free telephone service and its Web site, which includes chat rooms.
- Currently, there is no blood test for detecting cancer or a predisposition to cancer, although a few tumor markers have been discovered that can identify people with a genetic predisposition to certain cancers—for example, the relationship of BRCA1 and BRCA2 mutations to breast cancer. When a patient experiences multiple cancers, it can be difficult to determine whether these occurrences represent separate primary cancers or recurrences of one primary cancer.
- Once cancer has been diagnosed, disparities exist between the care received by people who know what to ask for and care received by people who do not know what to ask for. Patients with training or experience in medicine sometimes request options that oncologists fail to suggest. Existing print materials that are intended to help patients ask questions about their care are not routinely made available in oncologists' offices.
- Patient education would be more widely provided if the costs of these activities were reimbursable.
- Oncologists may not be able to help former patients with long-term problems related to cancer and its treatment because most insurance plans require patients to seek help from primary care physicians or other specialists after the course of cancer treatment has been completed. Nevertheless, survivors should contact their oncologists whenever they have questions or experience difficulty in persuading other doctors that their problems are cancer-related. Oncologists are willing to help their former patients choose a course of action to address such problems. Carrying a written history of medical treatment is a good start, but it is often helpful to obtain advice on specific options.
- Follow-up care for cancer survivors is best provided through networks of specialized, community-based cancer treatment centers. Services provided by the network of treatment centers in Alabama is

supported primarily through research grants and private donations. An evidence base is needed to demonstrate that insurance providers should cover follow-up of cancer survivors.

- Follow-up for adult survivors of childhood cancer is a crucial issue. The Alabama network is seeking grant funding to conduct research on what happens to pediatric surgical patients who are treated by network facilities but do not return to those facilities for long-term follow-up. Currently, there is no way to find out how many are treated at their referring hospitals, how many are treated by primary care physicians or other doctors, and how many are not treated at all.
- Training for oncology nurses takes the form of hands-on experience received by registered nurses, followed by certification exams. Exposure to survivorship issues varies depending on the individual practice setting. Nurses are more likely than doctors to become aware of survivorship issues and seek further knowledge through their professional associations.
- The NCI plans to initiate a study to track follow-up care for 1,600 survivors identified through tumor registries in California. A second part of the study will survey health care providers to ascertain their opinions and practices concerning follow-up care for cancer survivors.

TESTIMONY FROM PROVIDERS/INSURERS—GROUP II

Presenters

Dr. Alexander Hantel

Dr. Glen Mays

DR. ALEXANDER HANTEL

Background

Dr. Hantel is board certified in Internal Medicine and Medical Oncology. He received his medical degree from the University of Illinois and completed his internship and residency at the University of Illinois Hospitals, where he also served as Chief Resident. Dr. Hantel completed a fellowship in Medical Oncology at Johns Hopkins Oncology Center in Baltimore. Since 1988, he has been on the full-time faculty of the Loyola University Stritch School of Medicine, where he is currently an Associate Professor. He is also a member of the Cardinal Bernardin Cancer Center. Dr. Hantel is a member of the American Society of Clinical Oncology (ASCO) Breast Cancer Surveillance Expert Panel.

Key Points

- ASCO has prepared evidence-based guidelines for the long-term follow-up care of patients with breast cancer and colon cancer geared towards improving quantity and quality of life. The recommendations in the guidelines are based on a critical and rigorous review of the literature for scientific evidence of what actions are beneficial. Guidelines are published in the *Journal of Clinical Oncology* and on the ASCO Web site and are reviewed on an ongoing basis.
- The ASCO Guidelines Committee was made up of academic specialists in colon and breast cancer, practicing oncologists, cancer survivors, and experts in clinical guideline development and public health issues. The priorities for preparing the guideline recommendations were to determine: (1) factors that affect survival and disease-free survival; (2) factors that improve quality of life; (3) factors that reduce toxicity; and (4) cost-effective strategies.

- These guidelines have been used to develop patient guidelines for colon cancer and breast cancer. The NCCN has also established guidelines for patient treatment and follow-up care.
- The ASCO guidelines stress that it is extremely important for physicians to talk to patients at the end of their therapy, recognizing that emotional separation from the therapy team can be difficult. It is critical to explain the symptoms of cancer recurrence and define which symptoms need a doctor visit, as well as emphasize that the physician will always listen carefully to the patient.
- Optimal continuity of care, either by the primary care physician or the oncologist, is recommended to obtain a follow-up history and provide regular physical examinations. The guidelines recommend breast self-examination—even though the scientific benefits of doing so are ambiguous—as it is considered prudent for patients to develop familiarity with their own bodies. Annual mammograms and pelvic exams are also recommended.
- Routine blood tests, chest x-rays, and bone scans are not recommended because they are poor diagnostic indicators of breast cancer recurrence, and false positives can be also be damaging. Blood tests are, however, recommended for colon cancer. Explaining that there is a rational and scientific basis for the tests that are performed and their frequency may help patients accept the necessity for such tests.
- Important patient issues that are yet to be addressed in the guidelines include the health consequences of therapy, such as vasomotor symptoms, osteoporosis, and cardiotoxicity; screening for other cancers; family counseling and risk assessment; and maintaining long-term patient contact to impart relevant information on new medications. Good scientific information about assessing long-term effects is not yet available.

DR. GLEN MAYS

Background

Dr. Mays' research interests include quality incentive programs used by health plans, state health insurance reforms, and delivery and financing of local public health services. As a consulting researcher at the Center for Studying Health System Change (HSC), he studies economic and policy issues in managed care, health insurance, and programs for underserved populations. For the HSC Community Tracking Study, Dr. Mays analyzes trends in health insurance and managed care, including changes in benefit design, provider contracting, utilization management, and disease management approaches.

Key Points

- There is growing enthusiasm in the insurance industry and among employers for disease management models to better manage the health care needs of patients with chronic diseases such as cancer. Cost containment is one motivation; this is the fifth year of double-digit increases in health insurance premiums. Many of these costs are either passed on to employers and patients, or benefits are reduced.
- The Community Tracking Study monitors changes in local health care systems throughout the United States. Data on the health care available in 12 randomly selected markets with populations of at least 100,000 has been collected since 1996. Interviews are conducted with health care providers, medical groups, physicians' organizations, insurers, employers, and policy makers at the state and local levels to assess change, specifically in the disease management of chronic conditions.

- Disease management programs are more prevalent for chronic conditions such as cardiovascular disease, diabetes, and asthma. The complexity of breast and colon cancer treatment options makes identifying standards of practice more difficult from the insurance perspective. The costs are also more fragmented among different medical services.
- There is no strong evidence that any disease management program has a significant effect on either outcome or cost. This has been a stumbling block for health plans and employers wanting to invest in such programs.
- Cancer survivors are becoming an increasing presence in the workforce, and employers are pressing insurers to offer them new disease management programs. Four of the twelve markets tracked in the Community Tracking Study have introduced programs for cancer care, and health plans are offering a wider array of health insurance products. Health plans are promoting disease management programs and encouraging patients to participate, but only a fraction of potentially eligible patients have done so.
- Health plan membership turnover is also a problem. Patients move on to other health plans after the health provider has invested in a disease management program, so the benefits will not be evident over the short term.
- The basic objectives of disease management programs for cancer are: educating patients about their disease and supporting informed decision making regarding treatment options; reducing the level of fragmentation to lower costs; ensuring the delivery of the most appropriate and cost-effective settings (e.g., treatment as an outpatient rather than as an inpatient); and improving provider adherence to recommended, evidence-based guidelines.
- Disease management programs rely heavily on case management and case managers to coordinate patient care. Prior authorization of treatment is an important component. Some programs involve specialist provider networks and steer patients to selected cancer providers perceived as more efficient or effective in delivering care.
- Health providers in some markets are experimenting with incentives for patients (e.g., lower copays if the patient participates in a disease management program) and providers (e.g., financial incentives, exemptions from prior authorization review if guidelines are adhered to).
- Passing increased health care costs on to patients may create financial barriers that are in conflict with the effectiveness of disease management programs for patients with cancer.
- Coordination and continuation of patient care and drug benefits during the transition from private health insurance to Medicare is a challenge for health care providers and cancer patients.

DISCUSSION—PROVIDER/INSURER GROUP II

Key Points

- Women with early-stage breast cancer do not need to have bone and abdominal CT scans unless there is a specific medical reason for doing so.
- Financial incentives for providers in disease management plans involve bonuses for compliance with recommended clinical practice guidelines.

- Cancer care with a direct bearing on patients' quality of life (e.g., infertility correction, treatment for depression, physical rehabilitation) may not be specified in disease management program guidelines because it has no direct bearing on patient survival.
- Cancer treatment is highly individualized. Attempting to standardize guidelines to ensure uniformity of treatment and follow-up care may be incompatible with providing the most effective health care for each patient.
- Disease management program guidelines are not designed to address the follow-up care needs of those without insurance or in underserved populations.
- Patient anxiety and stress following completion of cancer treatment and separation from caregivers is being studied.

CLOSING REMARKS—DR. LEFFALL

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

**TOWN HALL MEETING
LIVING BEYOND CANCER: CHALLENGES FOR ADULT CANCER SURVIVORS
NOVEMBER 4, 2003**

In addition to the scheduled testimony, the President's Cancer Panel held a Town Hall Meeting to solicit input from the public on the challenges of living after diagnosis and treatment of cancer. [NOTE: The Town Hall Meeting was not limited to the concerns of adult cancer survivors, but was open to all cancer survivors, caregivers, and others affected by cancer.] Dr. LaSalle D. Leffall, Jr., Chair, Dr. Margaret Kripke, and Mr. Lance Armstrong represented the Panel. Dr. Maureen Wilson, the Panel's Executive Secretary and an Assistant Director of the NCI, was also in attendance. The meeting was moderated by Ms. Linda Mays, News Anchor and Medical Reporter.

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

- Dr. Leffall introduced members of the President's Cancer Panel and explained the purpose of the series of Panel meetings on survivorship and the goals of the Town Hall Meeting. He then introduced the moderator for the meeting: Ms. Linda Mays, daily news anchor and medical reporter for ABC 33/40, a Birmingham television station.

OPENING REMARKS—MS. MAYS

Ms. Mays explained the procedures to be followed during the Town Hall Meeting and introduced the first speaker.

MS. MARSHA WALTON

- Ms. Walton is a survivor of Hodgkin's disease and two occurrences of breast cancer. In 2002, she was diagnosed with congestive heart failure, a condition that was probably caused by the life-saving chemotherapy she received to treat her Hodgkin's disease.
- Survivorship clinics should be established nationwide to ensure that the needs of cancer survivors, such as monitoring long-term health effects of radiation and chemotherapy, are appropriately assessed and addressed.

MR. RON WILLIAMS

- Mr. Williams was diagnosed with bone cancer at the age of 15. He lost a leg to cancer, but the experience has given direction to his life. He believes that survivorship means not only surviving cancer, but helping others understand that cancer is not a death sentence.
- Efforts should be made to contact all cancer survivors to provide them with information guiding them to available sources of information, since finding these resources alone is difficult and time-consuming.
- Mr. Williams recently participated in the Bristol-Myers Squibb Tour of Hope, which was successful in raising awareness of the need for increased support for cancer research and participation in clinical trials.

MS. LOIS ZUSPAN

- Ms. Zuspan was diagnosed 20 years ago with uterine cancer following a hysterectomy; the cancer was treated with radiation. In 2001, she was diagnosed with lung cancer that could not be treated surgically because it had metastasized. She received radiation therapy and is still being treated with chemotherapy.
- Until recently, Ms. Zuspan continued to work as a sales representative. Because the drugs used in her treatment left her very weak, her husband accompanied her on business trips to help with lifting and carrying.
- Recently, the drug Ms. Zuspan was taking stopped working for her. At that time, enlargement of nodes in her neck left her with a paralyzed vocal cord. Although she has received speech therapy, her disability left her unable to continue working. She is now trying to determine what to do next in terms of treatment options.
- Evastan [*sic* Eloxatin?], a new drug approved for the treatment of colon cancer, is being considered for treatment of lung cancer. However, if Ms. Zuspan takes this drug, she will have to use it off-label at a cost of \$2,000 per month. Because she is unemployed and on Medicare, she cannot afford the drug.
- Genetic testing for cancer susceptibility should be provided at no cost to the patient. CT scans and PET scans should be made available without the long waiting period required for Medicare approval.
- Gail Hardin of the NCI's Cancer Information Service (CIS) urged Ms. Zuspan to call 1-800-4-CANCER to use CIS resources in locating a clinical trial that might meet her needs.

MR. PAUL SANDERS

- Mr. Sanders was diagnosed with prostate cancer ten years ago, at the age of 66. After radical prostatectomy, hormone therapy, and radiation treatment, his PSA level is now undetectable.
- Mr. Sanders feels that the Federal Government discriminates against research on cancers that affect men. He noted that 26 percent of each Federal research dollar is spent on HIV/AIDS, which causes fewer than 10,000 deaths per year in the United States; 16 percent on breast cancer, which results on 40,000 deaths; and 6 percent on prostate cancer, which results in 30,000 deaths.
- Funding for prostate cancer research by the NCI, the Department of Defense, and the CDC should be provided at the same level as support for breast cancer research. Paul stressed that he does not advocate reducing funding for other diseases, but rather, advocates for more aggressive leadership in supporting equitable funding for prostate cancer.
- Mr. Sanders recommended the book *Prostate Cancer for Dummies*, written by his surgeon, Dr. Paul Lang, of the University of Washington Medical Center. Mr. Sanders suggested that public libraries might be an excellent medium for dissemination of cancer information through books like Dr. Lang's and access to tools like the CIS.

MR. BILL ZUSPAN

- A positive attitude is difficult to maintain when recommended treatments have failed and the next step is unknown. Doctors have limited time to spend with individual patients to discuss the pros and cons of various treatments. A network is needed to help people with the same diagnosis and the same cancer history compare notes and share information on available options.

- Dr. Rowland noted that the Association for Cancer Online Resources maintains an international Web site (www.acors.org) that includes chat rooms for people with specific diagnoses. Questions can be posted for review by very small populations with similar interests.

MS. JUDY LUNDGREN

- Ms. Lundgren, President of the Oncology Nursing Society, noted that cancer is not a diagnosis affecting just a single person, but an experience that affects all of those who care for and about the person who is diagnosed and treated. The cancer experience is painful for these people, but they often feel guilty about expressing their own needs.
- Networks should be created to help family members and other caregivers locate hard-to-find resources and obtain relief from the stress they experience. These networks would also help caregivers learn how to communicate with medical care providers to ensure that patients' needs and problems are acknowledged and understood. This is especially important, as more patients are being treated near home rather than in hospitals.

MS. LYNN WAUGH

- Ms. Waugh, a former chemotherapy nurse in private practice, called attention to problems many cancer patients face in getting HMOs to cover the costs of chemotherapy. The oncologist she worked for treated one patient free of charge when her HMO flatly refused to cover treatment, but the cost is too high for physicians in private practice to cover all of their patients.

MR. SANFORD JEAMES

- Mr. Jeames, an education coordinator at the University of Alabama (UAB) Cancer Center and coordinator of a prostate clinic, asked the Panel what would be done with the information presented at this meeting. He was especially concerned about the lack of awareness of existing services and resources, particularly in rural areas and among people who do not have access to the Internet.
- Information and services provided to rural populations often lack coordination and follow-up. People may be told about their cancer risks but not what to do about them. People in rural areas who are diagnosed with cancer lack access to care; the facilities available to treat them are often many miles away.
- Dr. Leffall replied that the Panel will meet with staff from the NCI to review the testimony presented during the series of meetings on survivorship and develop conclusions and recommendations that will be spelled out in a final report. This report will be presented to the Secretary of Health and Human Services, the United States Congress, and the President's science advisors. This is not the first time the Panel has heard about the problems of disseminating information to rural areas, and this issue will continue to be a focus of the Panel's activities.

DR. NORMAN WALTON

- Dr. Walton spoke in favor of more aggressive and comprehensive efforts to promote cancer prevention, with an emphasis on diet, exercise, and other lifestyle factors associated with cancer risk. He noted that everyone is potentially a cancer survivor who has not yet been diagnosed. The enormous costs of cancer treatment can be reduced if an appropriate investment is made in prevention.

MS. GAIL LOWREY

- Ms. Lowrey, a representative of the Mid-South regional CIS office, called attention to 18 NCI-funded programs called Special Populations Networks (SPNs). Their purpose is to reach medically underserved populations, many of which are located in rural areas.
- The NCI's Physician Data Query (PDQ) service, available on the Internet as well as through the CIS, is designed to help patients find disease-specific information on treatment options. It also offers information on supportive care. The information is provided in two formats: one designed for health professionals and one for the lay public.

MR. LORI BLANTON

- Ms. Blanton, who works for the American Cancer Society, has lost six family members to cancer and is currently acting as a caregiver for her mother-in-law, who has breast cancer. She expressed concern about the many patients and caregivers who have never been taught to act as their own advocates in seeking out information, services, and support.
- In the state of Alabama, hospice funds will soon be reduced. This will mean reductions in medication support for Medicaid patients, including significant cuts in payment for pain medication. Patients in severe pain will have to wait two weeks before any payment is authorized.

DR. CHRISTOPHER TURNER

- Dr. Turner, a pediatric oncologist with the Dana-Farber Cancer Institute in Boston, noted that in the United States, availability of health insurance is usually associated with employment. People with a chronic disability, including many cancer survivors, are not able to work and are therefore unable to obtain insurance. This problem is compounded by the shift of emphasis in cancer care from inpatient to outpatient settings, placing an additional burden on the families of cancer patients, who take on many of the responsibilities of caregiving.

MR. THOMAS LOONEY

- Mr. Looney, a testicular cancer survivor, suggested that women have taken the lead in advocating for increased cancer research and information dissemination. Men have been less diligent in fulfilling their obligation to strive for improvements in cancer treatment. The standards of care for cancers that affect men have not improved much and often result in reduced quality of life.
- Education of the next generation is the key to improving outcomes for men affected by cancer. Mr. Looney is involved in efforts to initiate programs at the high school level—and eventually at the college level and among civic clubs and other community organizations. However, these initiatives will not succeed until men's cancer issues are acknowledged by government agencies and the media.

MS. FRANCINE HUCKABY

- Ms. Huckaby works with the Deep South Network, one of the NCI's SPNs. This project has trained more than 880 volunteer Community Health Advisors (CHAs) in Alabama and Mississippi in the basics of cancer, clinical trials, and information dissemination. Some of the training is provided by the American Cancer Society and the CIS. These CHAs touch many lives by providing information on cancer screening and treatment resources and recruiting people into clinical trials. The key to their success is that they come from within communities that do not trust outsiders. Funding for the SPNs

is up for renewal in the near future, and the Panel is urged to express its support for continuing these programs.

DR. BOONSEE YU

- Dr. Yu is a colon cancer survivor from New York State. When she completed her treatment, she began to make weekly trips to New York City to help bring cancer awareness to the Chinese community there. Her group makes presentations in religious institutions to promote cancer prevention and screening. She recommended a similar program for the rural areas of Alabama.

MR. CARLOS TORRES-SANCHEZ

- Mr. Torres-Sanchez came to the meeting to serve as an interpreter for Latino presenters with limited English proficiency. He works with a community-based organization that helps members of minority populations gain access to health care. Mr. Torres-Sanchez noted that there are more than 35 million people in the United States who speak languages other than English, many of whom are Latinos. For these people, the shortage of information about cancer survivorship is a greater problem than it is for the general population.

MS. ALISA GILBERT

- Ms. Gilbert is a Native American cancer survivor from the state of Alaska. She recently attended a networking conference for Native American survivors at the Santa Ana Pueblo in New Mexico. Ms. Gilbert stressed the importance of bringing information and resources to leaders at the grassroots level so that they can help educate their communities.

MS. TY HOWELL

- Ms. Howell is the librarian in charge of the UAB Comprehensive Cancer Center's new Cancer Resource Library, which was established for patients, family members, and cancer survivors—but not for doctors, who have access to the resources of medical libraries. The Library has a small book collection, a collection of pamphlets and other educational materials from sources such as the NCI and the American Cancer Society, Internet access, and relationships with local public and medical libraries through which Ms. Howell's staff can help people locate useful information. The library hopes to establish a relationship with the Deep South Network to serve as an information resource for that project. Other Comprehensive Cancer Centers have similar libraries.

MR. EMANUEL HAMELBURG

- Mr. Hamelburg is a 16-year prostate cancer survivor from Boston. Five years after his initial radiation treatment, he experienced a recurrence, with metastases to his spine and hip. He was treated at the NIH Clinical Center in an experimental program and has been cancer-free since then. His perspective on survivorship is that everyone who has had cancer always has cancer, whether it is active or not; there is no such thing as "beyond cancer." Mr. Hamelburg stressed the importance of keeping survivorship efforts focused on the long-term needs of people living with cancer, rather than being distracted by other issues such as screening and prevention, which are important but not central to the question of survivorship.
- Mr. Armstrong stated that while the meetings this year are focusing on survivorship, the Panel is committed to listening to whatever invited speakers have to say. The Panel's report will focus on the

topic of survivorship, but those who present testimony will not be restricted in what they would like to highlight in telling their own stories.

MS. ANASTASIA RODRIGUEZ

- Ms. Rodriguez spoke on behalf of four friends who are breast cancer survivors. Cancer affects not only cancer patients, but also everyone around them. Cancer education is needed by those who have friends with cancer and would like to be able to help them. HIPAA regulations, which are important in protecting patients, can also act as a stumbling block for friends who try to act on behalf of patients who are unable, for various reasons, to manage their own care.

CLOSING REMARKS— DR. KRIPKE, MR. ARMSTRONG, DR. ROWLAND, AND DR. LEFFALL

Dr. Leffall thanked Ms. Mays for her efforts as moderator and asked members of the Panel and NCI staff for their final remarks.

Dr. Kripke said that she was impressed by the power of individual voices in bringing the challenges of cancer survivorship to life for the Panel. She advised cancer survivors who wonder how they can make a difference to tell their stories to whoever will listen—including other cancer survivors as well as advisory panels and elected officials. The testimony heard at this meeting illustrates the frustrations and benefits of having a cancer diagnosis. The cancer experience can bring people closer together and bring clarity, purpose, and spiritual awakening to people's lives.

Frustrations occur in many areas, but four themes have become apparent. The first issue is insurance coverage. The cost of survival is very high, and the consequences of a cancer diagnosis for the uninsured and the underinsured can be catastrophic. Now that there are ten million cancer survivors in the United States, it may be time to develop the political will to address this problem. The second issue is access to information, not only about cancer but also about staying healthy after treatment. The third issue is the need for ancillary services that are not considered part of cancer treatment, such as psychosocial support, fertility treatment, rehabilitation, pain management, reconstructive surgery, and support for family members who become caregivers. The fourth issue is the need for long-term survivorship clinics and a system patients can use to maintain portable summaries of information about their cancer diagnosis, treatment, and follow-up.

Mr. Armstrong echoed the same concerns, noting that these themes have also emerged from Panel meetings on pediatric and young adult survivorship. He said that the best part of each Panel meeting for him is the testimony from real people because it provides the true flavor of what is going on in the fight against cancer.

Dr. Rowland said that the testimony presented at meetings of the Panel reinvigorates the NCI to continue its work and improve its resources to meet the needs expressed by survivors and caregivers. She described the problem of helping people in the survivorship phase of cancer as a “high-end” problem because it means that efforts to make cancer survivable are increasingly successful. Dr. Rowland has noticed that many cancer survivors are no longer satisfied with returning to their precancer health status, but instead they are eager to take advantage of the opportunities that survival brings to adopt a healthier lifestyle and make other changes to improve their lives. Survivors are asking for something that is not usually provided for the general population of adults—preventive health care. Dr. Rowland noted that the NCI has very little in its research portfolio so far that addresses the roles and needs of family members and other caregivers. They can play an important role in encouraging changes in lifestyle behavior following

diagnosis and treatment. She added that coding research projects is a complex problem, because many projects combine aspects of basic science and behavioral science. The research highlighted on the Web site of the NCI Office of Cancer Survivorship clearly focuses on post-treatment outcomes, but many projects in other research portfolios also deal in part with survivorship issues.

Dr. Rowland stressed the NCI's commitment to addressing cancer-related health disparities through activities like the SPNs described earlier and many other initiatives. For information on other directions the NCI is taking, she recommended the Institute's Bypass Budget, a blueprint for cancer research, submitted annually to the President and the Congress, that is developed with input from the scientific and advocacy communities. Finally, Dr. Rowland stated that the NCI will continue to return the results of taxpayer-supported research to the public, and she encouraged advocacy groups to continue to help disseminate this information in the community.

Ms. Mays noted that anyone who would like to provide the Panel with testimony but did not have an opportunity during the meeting is encouraged to submit that testimony in writing to Dr. Maureen Wilson, Executive Secretary of the President's Cancer Panel. A transcript and a summary of the meeting will be made available to the public.

CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President's Cancer Panel meeting, *Living Beyond Cancer: Meeting the Challenges of Adult Cancer Survivors*, held November 4, 2003, is accurate and complete.

Certified by: _____

Date: _____

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