

MEETING SUMMARY PRESIDENT'S CANCER PANEL

LIVING BEYOND CANCER: CHALLENGES FOR ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS

September 22, 2003
Austin, TX

OVERVIEW

The purpose of the meeting was to examine challenges of living after diagnosis and treatment of cancer for adolescents and young adults, 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 on issues related to cancer survivorship.

PARTICIPANTS

President's Cancer Panel

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

National Cancer Institute (NCI)

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, President's Cancer Panel
Andrew C. von Eschenbach, M.D., Director, NCI
Doug Ulman, Member, Director's Consumer Liaison Group

M. D. Anderson Cancer Center

Archie Bleyer, M.D., Chair, Adolescent and Young Adult (AYA) Committee, Children's Oncology Group (COG), and Director, Community Oncology Group

Centers for Disease Control and Prevention (CDC)

Nancy Lee, M.D., Director, Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion

Speakers

Tracy Cook-Brewton, Community Representative, North Carolina
Amy Dilbeck, Community Representative, California
Karen Dyer, Community Representative, New York
Tamika Felder, Community Representative, Maryland
Susan Leigh, Community Representative, Arizona
Michael Lin, Community Representative, Iowa
Craig Lustig, Community Representative, District of Columbia
Kathy Marsh, Community Representative, Michigan
Eric Rodriguez, Community Representative, Massachusetts

Octavio Zavala, Community Representative, California

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

On behalf of the PCP, Dr. Leffall welcomed invited participants and the public. Dr. Leffall also provided a brief overview of the history and purpose of the Panel and the aims of the current series of meetings on survivorship. He acknowledged two distinguished guests: Mr. Doug Ulman, representing the NCI Director's Consumer Liaison Group, and Dr. Nancy Lee, Director of the Division of Cancer Prevention and Control within the CDC's National Center for Chronic Disease Prevention and Health Promotion.

Dr. Leffall explained that this meeting would include testimony on the cancer survivorship experiences of individuals diagnosed with cancer between the ages of 15 and 30. Survivorship issues faced by this population include, but are not limited to, access to insurance coverage, ability to travel to specialized cancer centers, availability of psychosocial support services, and likelihood of complying with treatment regimens.

Dr. Leffall introduced NCI Director Dr. Andrew C. von Eschenbach.

NCI DIRECTOR'S REMARKS— DR. ANDREW C. von ESCHENBACH

- Dr. von Eschenbach began by asking for a moment of silence to acknowledge the millions of cancer patients and survivors unable to join today's meeting. He described the members of the PCP as extraordinary individuals well suited to carry out the Panel's mission. Their leadership in the areas of cancer care, research, and advocacy makes them uniquely qualified to incorporate what they learn during the Panel's meetings into recommendations for future policy.
- The National Cancer Act of 1971 charged the NCI not only with directly conducting and supporting cancer research, but also with providing leadership to the National Cancer Program (NCP), a term used to encompass the entire spectrum of public and private efforts to reduce the burden of cancer. Now, 30 years after passage of the Act, the NCP has reached a "magic moment" at which an understanding of cancer at the fundamental genetic, molecular, and cellular levels is coming together, along with rapid progress in implementing that knowledge through new interventions to detect, treat, and prevent cancer.
- In 1971, the year Lance Armstrong was born, the idea of surviving metastatic testicular cancer was only a dream. Discoveries in the 1970s and 1980s made it possible for Lance Armstrong to survive his cancer so completely that he was able to win the Tour de France five times. Based on the scientific progress that made this and other stories of cancer survivorship possible, Dr. von Eschenbach has issued a challenge to eliminate the suffering and death due to cancer by the year 2015. This does not mean eliminating cancer itself by that date, but rather, developing interventions to prevent the development of cancer, detect cancer as early as possible, and modify the progress of disease so that patients can live with cancer.

SURVIVORSHIP AMONG ADOLESCENTS AND YOUNG ADULTS: AN OVERVIEW— DR. ARCHIE BLEYER

Background

Dr. Bleyer is Mosbacher Chair Emeritus and Professor of Pediatrics at the University of Texas M. D. Anderson Cancer Center and Director of the M. D. Anderson Community Clinical Oncology

Program. His current clinical research mission is dedicated to young adults with cancer, a cohort that has not fared as well as either their younger or older colleagues. Dr. Bleyer is Chair of the Adolescent and Young Adult (AYA) Committee of the Children's Oncology Group (COG). He was assisted in developing his presentation by members of that committee.

Key Points

- Of the 9 million cancer survivors in the United States today, about 600,000 were diagnosed between the ages of 15 and 30, compared with 300,000 diagnosed at an earlier age.
- Two or three decades ago, children were considered an “orphaned” cancer population because they were poorly represented in research and published literature. Now that label can be applied to adolescents and young adults.
- Surveillance, Epidemiology, and End Results (SEER) data for patients diagnosed between the ages of 20 and 40 show that progress in cancer survivorship for this population has not kept pace with that for older and younger groups. The 20 to 25 age group has experienced the smallest reduction in cancer mortality of any age group. Cancer is the leading cause of death in the 20 to 40 age group.
- The relative lack of improvement in cancer survivorship for this population has resulted from inadequate knowledge, lack of clinical trial participation, failure to follow patients for extended periods, and lack of health insurance.
- A recent literature review showed that 33 percent of published papers about survivorship focused on pediatric cancer, while less than 1 percent focused on adolescents and young adults.
- Adolescents and young adults with cancer are less likely than older and younger patients to be referred to tertiary cancer centers or to participate in clinical trials.
- Less than 10 percent of patients diagnosed with cancer before the age of 15 are being followed 20 years later; follow-up rates for adolescents and young adults are believed to be even lower.
- Estimates of the number of Americans aged 18 to 24 who are uninsured range from 30 to 50 percent. Most of the insured members of this population have private insurance; few are covered by Medicaid or employer-provided insurance. This lack of coverage is associated with lack of access to clinical trials.
- A specialty discipline should be established to develop a body of knowledge about the unique features of cancers that affect adolescents and young adults and to train doctors to treat this population. Currently, the cancer survivorship research portfolio contains only six grants in this area. In the next review period, about 25 percent of the 125 submitted applications focus on pediatric cancer, but none focus on adolescents and young adults.

DISCUSSION—DR. BLEYER

- While developing the *Facing Forward* series of patient education booklets, the NCI acknowledged that the needs of young survivors are different from those of older survivors. Although the booklets place an emphasis on issues relevant to older survivors, young people are more likely to seek and read patient education materials. The NCI is considering development of a companion booklet on issues relevant to younger survivors.
- For years, research has focused on the tumor, but there is a growing understanding of the importance of interactions between the tumor and the host. Some forms of leukemia, for example, differ

according to the age of the patient. The adolescent and young adult population has special issues related to biological development as well as special psychosocial needs.

- Many cancers that occur among adolescents and young adults differ—whether in clinical presentation, histology, or biology—from the same cancers in children and older patients. These cancers require different interventions when diagnosed in the 15- to 29-year-old population.

STORIES FROM SURVIVORS—GROUP I

Presenters

Ms. Amy Dilbeck

Ms. Karen Dyer

Mr. Eric Rodriguez

Mr. Octavio Zavala

MS. AMY DILBECK

Background

In 1995, just before her 16th birthday, Amy was diagnosed with a four-inch tumor in her femur. A biopsy indicated that she had an extremely rare form of bone cancer, osteogenic sarcoma. Amy underwent aggressive chemotherapy and radiation treatments that ravaged her body and caused her to lose her hair. She received limb-salvage surgery to remove the tumor, her knee, bone tissue, and 25 percent of her quadriceps muscle. Titanium components were used to replace her knee and part of her leg. Amy encountered so much red tape working with her HMO that she needed an ombudsman advocate to help prevent lapses in her treatment. Amy has become an advocate through her work with the National Childhood Cancer Foundation.

Key Points

- Becoming a cancer survivor has strengthened Amy's sense of purpose in life.
- Amy's parents were terrified at her diagnosis because 20 years earlier, her mother's high school friend, who had the same diagnosis, died shortly after her senior year. Her doctors explained that Amy's outlook was very different, although even with the most aggressive treatment, her chance of surviving was only 80 percent.
- Adolescents and young adults with cancer fight to keep their lives as normal as possible. They experience conflict between their desire for privacy and their desire to have others understand what they are going through.
- Amy learned through a friend who was a medical student that she should be taking calcium; her doctor had forgotten to tell her about this. Follow-up of cancer patients would be improved by developing a specialty in survivorship so that survivors' long-term needs could be addressed by physicians specifically trained in that area. Since survivorship specialists are not available in every hospital and community, there should also be a centralized source of information for survivors who are proactive in managing their own long-term care.
- Adolescent and young adult cancer patients need role models like Lance Armstrong to provide encouragement during treatment and their transition from patient to survivor.

MS. KAREN DYER

Background

Karen was diagnosed with alveolar rhabdomyosarcoma eight years ago, at the age of 15. She received chemotherapy, radiation therapy, and an autologous stem cell rescue. Karen has received good follow-up medical care, but her doctors did not take the initiative in addressing other issues; although her hospital has a post-treatment psychosocial program, she did not learn about it until five years after her treatment. Cancer was financially devastating for Karen's family; her doctors were not fully covered by her insurance, and some treatments (such as stem cell rescue) were not considered standard care and were, therefore, not covered.

Key Points

- Karen's concerns as a cancer survivor evolved over time following treatment. At first, she did not ask questions beyond what she needed to know to live from day to day. She gradually began to think about the future and became proactive in her own health care. Now she worries about a variety of issues, from recurrence to secondary cancer to long-term effects of treatment, such as premature menopause caused by chemotherapy.
- Practical issues are also concerns for cancer survivors, including employment discrimination, difficulty in obtaining insurance, and finding a new health care team when relocating.
- Karen found it difficult to make the transition back into school after treatment. She went from being the center of attention to feeling isolated and abandoned. She had trouble fitting in, both because she was out of touch with adolescent trends and because her experiences made her feel different from other students. Although school personnel tried to be supportive, they lacked the training needed to help her reenter the school environment.
- A patient-matching system would help cancer patients who are completing treatment make connections with survivors who have had similar experiences.
- Much of the information available concerning rare cancers, such as rhabdomyosarcoma, is found in medical journals that are not easy for most patients to interpret.
- Karen was amazed at the amount of information that became accessible to her when she began working with a breast cancer advocacy organization. This information should be made more easily accessible to all cancer patients and their families.

MR. ERIC RODRIGUEZ

Background

Eric was diagnosed with optic glioma in 1991, at age 15, and underwent surgery. The tumor was very close to the optic nerve; his doctors removed only 80 percent in order to preserve some of Eric's vision. The other 20 percent of the tumor was treated with radiation. Eric is legally blind in his left eye and has only 50 percent vision in his right eye. The part of the tumor treated with radiation is gradually shrinking. As a side effect of radiation therapy, Eric developed leukoplakia on his tongue, resulting in the removal of half that organ. Long before his cancer diagnosis, he was already experiencing endocrine problems, as the tumor had affected his pituitary gland. Before the tumor was detected, he was misdiagnosed as having a learning disability.

Key Points

- Cancer survivors long for a “normal” life, but they are often forced to give up their favorite activities and become accustomed to frequent medical checkups and procedures.
- Adolescent and young adult cancer patients are often caught between the pediatric and adult health care systems. When he received radiation therapy, Eric had to be transferred from Children’s Hospital in Boston to Brigham and Women’s Hospital because the pediatric hospital did not have radiation equipment large enough to accommodate a 15-year-old patient.
- Although he is blind in one eye and has no peripheral vision in the other, Eric has earned a master’s degree in medical illustration and operates his own business from a home office. He was assisted in setting up his business by the Dana-Farber Cancer Institute and the Massachusetts Rehabilitation Center.
- One important reason for starting his own business was to obtain health insurance. Because of Eric’s advanced level of education, social services stopped providing him with assistance.

MR. OCTAVIO ZAVALA

Background

Octavio was diagnosed with acute lymphoblastic leukemia in 1984, at the age of 12, and was treated with chemotherapy and cranial radiation. Octavio went through a very difficult time fighting his cancer—not only physically but also socially. After his treatment, he had a lot of catching up to do to fit in socially and face his fears about the future. Octavio currently works at Children’s Hospital in Los Angeles, where he coordinates psychosocial and support services for cancer survivors and conducts research on psychological issues affecting cancer survivors and their families.

Key Points

- Although Octavio was diagnosed with cancer before he became an adolescent, his treatment extended through his teen years, and his survivorship experience has been similar to that of other adolescent and young adult cancer patients.
- From diagnosis through treatment, care of a cancer patient focuses on medical issues and often overlooks psychosocial concerns. While he was being treated, Octavio’s social growth was inhibited, and he exhibited regressive behavior that lasted long after treatment. When he entered college, he lacked the independence, resourcefulness, and social skills necessary for success.
- Octavio did not receive adequate information as a patient about his disease and its treatment. Only when he found a book about leukemia on his own did he learn that leukemia is a form of cancer.
- Peer-based support for cancer patients would help build social skills. Few adolescent cancer patients know anyone else who has cancer.
- Preparation for life after cancer—including orientation to the medical system, information about insurance issues, and training in problem-solving skills—should be provided for all cancer patients. Octavio did not learn much about late-term effects, such as cardiotoxicity, until ten years after his treatment ended. During those ten years, he engaged in some activities, such as lifting weights, that he should have avoided.

- HMOs and other insurers often refuse to pay for follow-up care unless a cancer patient is symptomatic. Octavio receives consultation services from Children's Hospital in Los Angeles, but he cannot afford to pay for follow-up echocardiograms, MRIs, or bone density scans.

DISCUSSION—GROUP I

Key Points

- Adolescent and young adult cancer patients are often offered on-on-one psychological consultation, but what they really want is peer-to-peer support. Frequent interaction with peers who are not cancer patients is also essential.
- Adolescent and young adult cancer survivors often do not have enough free time to address psychosocial issues until after treatment and education have concluded. By that time, they are ready to put their experiences into perspective and join efforts to help others with similar experiences.
- Cancer advocacy organizations that hire cancer survivors benefit by learning about insurance issues faced by survivors and by utilizing the insights of staff members who are former cancer patients.
- Cancer survivors who lose health insurance for any reason are faced with barriers when seeking new coverage because they are determined to have preexisting conditions.
- Child-life specialists participate in health care teams for pediatric cancer patients. Training and service delivery programs for adolescent-life specialists are needed for the adolescent and young adult population.
- The Children's Oncology Group is developing a comprehensive Web-based guide to long-term follow-up. A similar resource should be developed for adolescents and young adults.
- Existing cancer registries, such as those developed by the states, the CDC, the American College of Surgeons, and the Children's Oncology Group, could be used as a starting point to build the infrastructure needed to conduct long-term follow-up and provide individualized information to survivors about late effects of treatment and long-term health care needs. A coordinated effort would be required to capture the large numbers of adolescents and young adults who do not participate in clinical trials.
- An effective follow-up tracking system will need to have more detailed medical histories than most existing registries contain. New Health Insurance Portability and Accountability Act (HIPAA) regulations will make this task even more difficult. The NCI and other organizations will need input from the survivor community on the best approaches to sharing medical information and research findings to achieve optimal outcomes.
- Because many adolescent cancer patients are treated in pediatric care settings, they are overly sheltered and experience a loss of control over their treatment and their lives. Learning about cancer and its treatment alleviates fear and helps adolescents prepare for the future.

STORIES FROM SURVIVORS—GROUP II

Presenters

Mr. Michael Lin
Mr. Craig Lustig
Ms. Kathy Marsh

MR. MICHAEL LIN

Background

Michael is a 22-year-old Hodgkin's disease survivor with a degree in biomedical engineering. He was diagnosed at the age of 20 and was treated with chemotherapy and radiation therapy. Michael has been in remission for almost two years. He feels that it would have been easier for him to move forward if he had received information from his doctors about psychosocial resources. Michael has participated as a counselor at Camp Dream Street and is an intern with the Lance Armstrong Foundation.

Key Points

- Michael's cancer treatment was successful, and he felt that the care he received was excellent. After treatment ended, however, he felt that he had been left sitting alone on the sidelines to wonder what would happen next. Each time he felt a sore throat or a snuffle, he worried that he was experiencing a cancer recurrence.
- As both a cancer survivor and a college student on the verge of making major life decisions, Michael was torn between the need to study and take care of his health and the impulse to have fun and live life to the fullest.
- Michael experienced depression during his treatment but chose not to seek counseling because he did not want to admit that something was wrong. He concentrated on his studies in order to continue living as normal a life as possible.
- Michael's doctors discussed side effects of treatment but did not discuss late-term effects and never raised the issue of psychological or social problems. A friend of the family who was a Hodgkin's lymphoma survivor helped Michael deal with these issues. He also attended a camp for young adults with life-threatening illnesses, and talking to other survivors helped him address the long-term effects of treatment and the social issues faced by survivors. Seeing a documentary that featured a 20-year survivor of cancer motivated Michael to stop sitting at the crossroads of his life wondering which way to go.
- The literature on cancer survivorship tends to cover only the five-year period following treatment. Little attention has been paid to the experiences and needs of cancer survivors beyond that period.

MR. CRAIG LUSTIG

Background

Craig was diagnosed with a brain tumor in 1992, at the age of 27. He received surgical treatment and was enrolled in a clinical trial that used only chemotherapy. When he experienced a recurrence in 1994, he was treated with a combination of chemotherapy and radiation. It has taken him a long time to work through emotional issues related to the long-term effects of his treatment, and he feels he still does not

have enough information on follow-up care and diagnostic tests he should obtain in the future. Craig is now employed by an advocacy group called Children's Cause, serving as vice president for the organization's survivorship program. He uses his own experience as a survivor in helping other young adults deal with cancer.

Key Points

- A team approach was used to provide coordinated, comprehensive care when Craig underwent chemotherapy and radiation treatment in a pediatric oncology unit. However, this coordination and quality of care did not extend to the period immediately following his treatment in that specialized unit. Lack of communication between hospital staff monitoring Craig's nonacute health problems and the pediatric oncology team led to what he feels were unnecessarily long hospitalizations and inappropriate treatment.
- Craig's post-treatment follow-up plan focused on monitoring for recurrence and neurological changes. Craig was responsible for managing follow-up visits and coordinating communications between physicians. The possibility of late effects of cancer treatment was not mentioned. Craig feels that the relationship between his cancer, its treatment, and his subsequent health problems is poorly understood by the various doctors he has consulted.
- Survivors and their families should be provided with follow-up plans that cover potential late effects, psychosocial issues, and other long-term concerns. These plans should provide guidance on obtaining care when late-term effects occur. A nurse practitioner or other health care provider should coordinate long-term care and provide information needed by survivors instead of survivors being expected to coordinate their own care.
- As a professional advocate, Craig hears many stories of cancer survivors previously covered by their parents' health insurance who have trouble obtaining their own coverage as young adults.
- Many adolescent and young adult cancer survivors will live decades beyond their acute cancer experiences. Their potential as individuals and their potential benefit to society as citizens should not go unrealized because of inadequate follow-up systems and discriminatory insurance policies.

MS. KATHY MARSH

Background

Kathy was diagnosed with Hodgkin's disease in 1975, at the age of 20, and received radiation and surgery. After her spleen was removed, she was particularly conscious of her compromised immune system; however, she now feels that her body has compensated, her immune system is strong, and she is healthy. Cancer is very prevalent in Kathy's family. Her father was diagnosed with colon cancer one year before her own diagnosis and died in 1976; her grandmother, cousin, two aunts, and a sister have had cancer. When she was married, she told her husband that she fully expects to get breast cancer; in her mind, the question is not if, but when.

Key Points

- Being diagnosed with cancer often presents difficult choices for college students, who must decide whether to let their treatment interfere with their educational plans. These choices will have dramatic effects on the rest of their lives. Because she was diagnosed in late spring, Kathy decided to devote the summer months to treatment but was determined to continue her education and was only two days late starting the fall semester.

- When she was diagnosed with cancer, Kathy was sent from rural Michigan to Detroit for treatment. The hospital there had access to a new protocol for staging and treating Hodgkin's disease that would not have been available to her if she had been treated closer to home. Because her family lived so far away from Detroit, Kathy was forced to live with her aunt while receiving treatment.
- While Kathy was undergoing treatment, her father was being treated for colon cancer. He read about Hodgkin's disease in an outdated medical book and assumed that his daughter had a fatal illness. As a result, he tried to protect her from learning anything further about her condition.
- For ten years following treatment, Kathy moved several times, and each time she was required to find new doctors, including oncologists. Now that she is settled back in Northern Michigan, she has decided to reduce her schedule of annual visits to physicians by relying on her gynecologist for regular follow-up of her Hodgkin's disease. She was fortunate to find a gynecologist willing to provide her with this support.
- Because of her family's history of breast and other cancers, Kathy has a matter-of-fact attitude about her likelihood of being diagnosed with breast cancer at some point in the future. She is especially concerned about the effect of her 1975 radiation therapy on that risk.

DISCUSSION—GROUP II

Key Points

- To illustrate how much progress has been made in cancer treatment, Dr. Leffall noted that when he entered medical school in 1948, Hodgkin's disease and leukemia were incurable cancers, and patients with osteogenic sarcoma had a 15 percent survival rate. In the 1970s, when Kathy Marsh underwent a splenectomy, vaccines and antibiotics routinely used today to reduce infection risks associated with that procedure were not available.
- Having one place to go for medical follow-up is a useful innovation for survivors in rural areas—if doctors as dedicated as Kathy's gynecologist can be found. For survivors in urban areas, seeing multiple specialists is not a problem if communication among those specialists is properly coordinated.
- The stories of cancer survivors should not be treated as if they were fictional plots with a beginning, middle, and end, but as histories that can be shared to lay down a path for the future.
- The Community Clinical Oncology Programs (CCOPs) were established to provide cancer patients in rural areas with access to clinical trials. Most adolescents and young adults are not referred to tertiary centers as Kathy was; they are treated by oncologists in the community. An organized effort at the national level should make it possible to follow these patients.
- Gynecologists, internists, family practitioners, and other medical specialists need training in detecting cancer and managing its treatment.
- As long-term cancer survivors begin to see more specialists and have reduced access to their oncologists, they need guidelines and standards of care that they can present to their specialists, as well as to their primary care physicians.
- Parents, families, and friends of cancer patients need guidance and accurate information to help them provide appropriate care and support and to help them cope with their own stress associated with the cancer experience.

- The Texas Children’s Cancer Center in Houston, with the support of the Texas Cancer Council, has established an Internet-based resource to provide survivors with individualized long-term care guidelines that can be regularly updated as new information becomes available.
- Testimony provided by cancer survivors indicates that many are motivated to dedicate their professional lives to cancer research, service delivery, or advocacy, not only to share their experience with others, but also to continue learning from fellow survivors.
- Over the past 20 years, standards of care for pediatric cancer have evolved from clinical trial protocols. It is more difficult to develop standards of care from protocols used in clinical trials for adults because less than five percent of adults participate in those trials.
- Standards for follow-up care for survivors are more complicated than standards for cancer treatment. The history of long-term cancer survivorship is short, and information on the kinds of follow-up care needed is limited. Individuals have very different problems, even when they have the same kind of cancer. Therefore, standards of care for follow-up need to be carefully constructed. Once anything is identified as a standard procedure, legal challenges could be brought forth if that procedure is not followed, even though it may not be called for by an individual survivor’s circumstances.

STORIES FROM SURVIVORS—GROUP III

Presenters

Ms. Tracy Cook-Brewton

Ms. Tamika Felder

Ms. Susan Leigh

MS. TRACY COOK-BREWTON

Background

Tracy was 26 years old in 1997 when she discovered a lump in her left breast. At that time, she had a four-year-old daughter and a one-year-old son. Tracy decided on breast reconstruction following surgery and chemotherapy, but she later had the implant removed because she was in constant pain and doctors continued to see suspicious areas behind the reconstruction. Throughout her treatment, Tracy served as her own advocate and did extensive research about breast cancer in young adults. Because of her family history of breast cancer, she underwent genetic testing, learned that she had BRCA1 and BRCA2 mutations, and elected to have her ovaries removed—a difficult decision because Tracy and her husband wanted to have more children.

Key Points

- When Tracy began her research about breast cancer, she found that most available information focused on older women. Tracy was unable to find breast cancer support groups in her area, so she had to attend groups that included people affected by all types of cancer, most of them older than Tracy. It was difficult to find anyone with experiences and concerns similar to hers.
- Part of being a cancer survivor is living in fear of recurrence. Tracy has had five biopsies since her initial diagnosis. She is considering a prophylactic mastectomy but is concerned about whether her insurance will pay for the procedure.

- Tracy was passed over for a promotion because of the amount of time she had to spend away from work during her treatment due to surgery and chemotherapy. Although she would prefer to change jobs, fear of losing her insurance has kept her in the same position. Tracy has been denied an increase in her life insurance coverage even though her physician has explained that she is cancer-free.
- Cancer care has become more patient-centered in recent years, but it needs to become more family-centered. Tracy's husband stood by her and worked hard to help care for her, but there was no psychosocial support to help him deal with the experience.

MS. TAMIKA FELDER

Background

Tamika was diagnosed with cervical cancer three years ago, at the age of 25, and was treated with a hysterectomy, chemotherapy, and radiation therapy. She completed her treatment in 2001. Tamika says that cancer has been both the worst and the best thing that ever happened to her. It has been an exhausting battle physically, emotionally, and financially, but it has also been a wake-up call that has helped her mature in many ways. The most difficult issue for Tamika after her treatment has been the emotional impact of infertility.

Key Points

- Cancer has always been a part of Tamika's life—she lost her father to colon cancer and two uncles to bone and prostate cancer—but at the age of 25, she was in denial about the possibility that she herself might be diagnosed with the disease.
- It was difficult for Tamika to believe that in order to save her own life, she had to make the decision to have her uterus removed.
- Tamika's cancer took a heavy toll on her mother. Tamika often felt that she had to put on a brave face for her mother's sake.
- Even though Tamika had a good job with good health insurance coverage, she still owes her hospital thousands of dollars.
- Tamika learned too late about an organization called Fertile Hope that might have been able to help her find a way to preserve her fertility during her treatment for cervical cancer.
- Tamika received good medical care but felt abandoned on her last day of treatment. She was told that the cancer was gone and she looked great, but no one prepared her for the emotional issues she was facing. A nurse said, "If you need anything, call me," but she meant medications, not psychosocial support.

MS. SUSAN LEIGH

Background

Susan is a 56-year-old three-time cancer survivor. She was first diagnosed with Hodgkin's disease at the age of 24 upon her return from Vietnam, where she served as an Army nurse. Following treatment, she remained cancer-free until she was diagnosed with breast cancer in 1990 and underwent a bilateral mastectomy. Five years later, at the age of 48, she was diagnosed with bladder cancer. As a result of her cancer experience, Susan became an oncology nurse and helped found the National Coalition for Cancer

Survivorship (NCCS) in 1986. She is concerned that there are no guidelines for long-term follow-up care and no standards of care available for primary care physicians who care for most survivors after oncology treatment has concluded.

Key Points

- More than 30 years since Susan was first diagnosed with cancer, there are still cancer patients and survivors with unmet needs, and some people are still unaware of the few resources that are available.
- Because she is uninsurable, Susan is grateful to the Department of Veterans Affairs hospital system for providing her with very good medical care without leaving her family financially devastated. However, at her time of diagnosis, the VA had little experience with young women, and its doctors were insensitive to her sense of loss when she learned that she would be infertile. Their response was, “We are going to cure you...what more do you want?”
- After her initial treatment for Hodgkin’s disease, Susan decided to specialize in oncology nursing, a new discipline at that time. Her experiences in this nursing specialty opened her eyes to her own issues related to long-term survival.
- Susan’s breast cancer, diagnosed in 1990, was probably caused by the extensive radiation treatment she received in the 1970s. At that time, protocols for treating Hodgkin’s disease were still evolving, and her treatment was probably overly aggressive.
- Options are limited for a person diagnosed with a second cancer. Because she had received so much radiation already, Susan’s breast cancer was treated surgically, including a prophylactic mastectomy on the contralateral side.
- Survival will continue to be a trial-and-error process for each cancer patient until long-term follow-up and rehabilitation become standards of care. Models developed for pediatric cancer survivors should be adapted for adults. Survival follow-up clinics should have a wellness focus and also an educational component.
- When patients leave treatment, they should be assisted in collecting and maintaining copies of their diagnostic, pathology, and treatment records.
- There is a critical need for psychosocial support occurs when patients complete their treatment. This is a time when they are frightened by every lump, headache, and sore throat. New survivors need to learn how to trust their bodies again.
- Prevention efforts are needed to protect survivors from recurrence, secondary cancers, and late effects of treatment.

DISCUSSION—GROUP III

Key Points

- When cancer patients complete treatment and return to work, employers often assume they have no further problems related to cancer. Employers are reluctant to make accommodations for late effects or psychosocial consequences of treatment.
- In considering testimony about the late effects of treatment and long-term care issues, the added burden carried by those who are uninsured or underinsured must be considered.

- Because delayed diagnosis is a problem for young adults, it might be worthwhile to compare outcomes in the general population with those in the VA system.
- Survivorship issues should be added as a major component of training for oncologists and nurses.
- An organization called Leap of Faith comprises 40 skydivers who are cancer survivors. The group has visited camps for pediatric cancer patients by jumping into the campgrounds. Leap of Faith's five-year goal is to open a camp called Camp Extreme featuring skydiving, water-skiing, and similar activities.
- Survivors want their care providers to give them a more positive attitude toward survivorship by helping them focus on wellness. They want information on diet, exercise, and ways to deal with stress and anxiety. Complementary therapies should be incorporated into long-term follow-up care. It might be beneficial, for example, to incorporate massage therapy, yoga, and meditation into follow-up.
- Education and counseling provided when cancer patients receive genetic testing is often inadequate.
- The most significant event in the movement to improve the lives of cancer patients may have been the coining of the word *survivorship*. The NCCS defines survivorship as beginning at the moment of diagnosis and continuing through the rest of a survivor's life, because the process of survival includes all decisions and actions following diagnosis. The term was coined in 1986 to curtail the identification of cancer patients as victims. Other terms—such as *advocates*, *activists*, *consumers*, *thrivers*, and *clients*—are preferred by some.
- Cervical cancer is underrepresented among cancer support groups. A pop music artist and cervical cancer survivor in Boston named Christine Baze has created a nonprofit organization called popsmeat.org and is organizing benefit concerts to raise awareness of this disease.

CLOSING REMARKS—DR. LEFFALL

Before adjourning the meeting, Dr. Leffall asked all speakers to gather at the front of the room to receive recognition of their participation. He reminded participants of the evening Town Hall Meeting and the upcoming Panel meeting in Birmingham, Alabama.

**TOWN HALL MEETING
LIVING BEYOND CANCER: CHALLENGES FOR ADOLESCENT AND YOUNG
ADULT CANCER SURVIVORS
SEPTEMBER 22, 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 pediatric 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, and Dr. Andrew von Eschenbach, Director of the NCI, were also in attendance. The meeting was moderated by Mr. Kirk Watson, former Mayor of Austin, Texas.

INTRODUCTION—DR. LEFFALL

- Dr. Leffall introduced members of the President's Cancer Panel and Mr. Kirk Watson.

OPENING REMARKS—MR. WATSON

Mr. Watson, who was a testicular cancer survivor before he became mayor of Austin, noted that on the day he announced his candidacy, Lance Armstrong announced that he had testicular cancer, and all media attention turned and focused on Mr. Armstrong's story. Mr. Watson took advantage of this coincidence by expressing his belief that cancer patients can survive their disease, pointing out as an illustration the fact that he himself had just announced his candidacy for mayor.

Mr. Watson explained the procedures to be followed during the Town Hall Meeting and introduced the first speaker.

MS. HEIDI SCHULTZ ADAMS

- Adolescents and young adults who seek peer support or educational materials find that most resources focus on the needs of people either much younger or much older than they are.
- The best way to ensure that adolescent and young adult survivors can be tracked for long-term care is to reach them when they are in treatment. Survivors should be told that they need to serve as their own advocates and take control of their health care.
- Patients and survivors in this age group have a hard time locating each other to form support groups—as well as finding time to participate in them. Because they are busy trying to get on with their lives, it is better to help them provide each other with information and support on demand rather than ask them to wait for a scheduled support group meeting to express their needs. Peer support can be as simple as one survivor encouraging another to get a checkup—and perhaps even going with that person to provide moral support. Ms. Schultz Adams has launched Planet Cancer (planetcancer.com), a Web site for young adults with cancer, to deal with some of these issues.

MS. PATRICIA WILSON RODRIGUEZ

- In 1989, Patricia was diagnosed with stage IV non-Hodgkin's lymphoma. During her ten-year battle with cancer, her husband was diagnosed with and eventually died from colon cancer. Patricia is now in remission but still has a feeding tube (a portacath). She now has Barrett's esophagus, a precancerous condition, and is prepared to fight cancer again in the future, if necessary. Before her cancer was diagnosed, Patricia was a registered nurse; now she works as a clinical assistant, listening to the concerns of patients and letting them know she has walked in their shoes.

MR. CHARLES JOHANSON

- Charles, 63, recently completed treatment for Hodgkin's disease. He is offended when people say that he is lucky to be cancer-free because he feels that cancer is something he defeated through a positive attitude.

MS. GLORIA JEAN MOORE

- Gloria, a 23-year Hodgkin's disease survivor, started her own business in 1986, just before the COBRA laws went into effect. For 12 years she had no health insurance because no one was willing to cover her. Because she is from the U.S.-Mexico border area, she was able to obtain medical care in Mexico at a reasonable cost. In 1997, she was finally able to obtain insurance, but at a high premium that has steadily risen since then.
- Gloria learned the value of keeping track of her own medical records the hard way. She had a suspicious Pap test, but the hospital told her that obtaining the records of her cancer treatment was not necessary. She underwent a staging laparotomy, and it was learned that the problem was caused by scar tissue from her earlier surgery.
- In 2002, Gloria was diagnosed with breast cancer, and she was told that it was probably caused by radiation exposure. This was an outcome she had not been prepared for by the doctors who had treated her first cancer. She obtained second and third opinions from teaching hospitals and decided on a bilateral mastectomy.
- It is difficult to save for retirement when one has to pay almost \$1,000 per month for health insurance.
- Gloria urged the Panel to help educate all doctors and nurses about the high incidence of second cancers. Patients should be told what tests to obtain at various points in time after receiving radiation therapy. This information should be repeated when survivors are contacted for any reason, such as collection of survivorship data or solicitation of donations for treatment centers.
- Some form of Government-supported health insurance should be provided to self-employed cancer survivors.

MS. CRYSTAL GRIFFITH

- Crystal was diagnosed with Acute Lymphoblastic Leukemia (ALL) in 1982. Although she was told her life expectancy was poor and that she would never be able to have children, she has survived 22 years and has three children. Crystal supports improved public education on childhood cancer to prevent the kind of cruel treatment she received from other children.

MR. JUAN SANCHEZ

- Juan spoke on behalf of his brother, Louis, who was diagnosed with non-Hodgkin's lymphoma in February 2003. Louis has completed a series of chemotherapy treatments and is beginning radiation therapy. His doctors are hopeful that his tumor will be completely eradicated.
- When his symptoms first appeared, Louis was told they were caused by allergies. He had to visit several times before his doctor was persuaded to run the tests that confirmed his cancer diagnosis.
- The most frustrating aspect of the cancer experience for Louis has been putting his career on hold. He had just completed his degree in criminal justice and psychology and was about to enter the San Antonio Police Academy. He has also had problems convincing the Social Security Administration of the severity of his condition.

MS. MELISSA OLIVE

- Melissa was diagnosed a year ago with a rare form of non-Hodgkin's lymphoma that affects soft tissue rather than lymph nodes. Her doctors in Austin wanted to apply low-beam radiation to the conjunctiva of her eyes without using protective measures. She searched the cancer literature and learned that the current standard practice is to use lens blocks to prevent exposure that could lead to secondary cancers. She contacted the M. D. Anderson Cancer Center, where she received treatment using lens blocks.
- Although Melissa has good insurance, she experienced problems with billing. She had to be very assertive to avoid paying for expenses that were covered by her policy. She worries that less assertive and less well-educated patients might go broke paying bills that are not their responsibility.

MR. JERRY JOHNSON

- Jerry is a 60-year-old survivor of non-Hodgkin's lymphoma and prostate cancer. According to the International Bone Marrow Transplant Registry, he is one of only 500 ten-year survivors of an autologous bone marrow transplant among more than 11,000 who received transplants between 1989 and 1992.
- Jerry is unable to obtain credit due to financial hardships experienced during his years of treatment. Financial institutions should establish compassionate policies for people who experience catastrophic illnesses; for example, they could waive penalties, provide flexible payoff solutions, reduce the paperwork burden, and freeze balances and interest.
- Having lost his job in 2002, when he was diagnosed with prostate cancer, Jerry has been forced to file for bankruptcy. He is unable to find a new job because companies are unwilling to hire and train a 60-year-old man with short-term memory problems and other disabilities resulting from cancer treatment.

MR. FRED DREWE

- Fred, at age 56, has spent half of his life as a testicular cancer survivor.
- Cancer patients must take the initiative to ensure that their doctors provide them with the best possible care. If a doctor does not suggest getting a second opinion, the patient should get second and third opinions and stop seeing the first doctor. The same initiative should be taken when treatment has

ended and follow-up care begins. Many doctors do not keep up with the literature on long-term effects of cancer treatment.

- Internet resources are useful, but not everyone has access to the Internet. Information should be disseminated through a wide variety of outlets to make sure it is available to everyone.

MS. JUANITA TISERINA

- Juanita's son was diagnosed with retroperitoneal sarcoma at age 26. An oncologist in Austin told her he did not know who treated sarcoma, but that he would get back to her. In the meantime, she located a sarcoma unit at M. D. Anderson and was able, after solving some problems with insurance, to get her son into that unit. He has been cancer-free for the past six years.
- When her son was diagnosed, Juanita thought that cancer was an old person's disease. People were afraid to talk about cancer, believing that a cancer diagnosis was a death sentence. During her lonely nights at M. D. Anderson, Juanita decided to use her communications education and experience to help increase awareness of cancer. She collected petition signatures supporting increased funding for cancer research.
- Juanita's son experienced nightmares and other psychological problems during his treatment; although his medical care was excellent, his doctors were not helpful in dealing with psychological issues. Her son managed to overcome these difficulties by relying on role models like Lance Armstrong.

MS. DEBBIE HOLLAR

- Having finished her last chemotherapy treatment earlier that day, Debbie stressed the importance of coordinated post-treatment care to help cancer survivors find the right direction in dealing with issues such as nutrition and spiritual and emotional well-being.
- A database should be created to help cancer survivors understand what to expect and to provide step-by-step guidance for follow-up care.

MS. SUZANNA McVEY

- Suzanna is a third-generation breast cancer survivor. When she was diagnosed with breast cancer, her primary care doctor gave her the news, referred her to a surgeon, and said goodbye. He provided no educational materials and said nothing about the availability of support groups. Suzanna was lucky to be able to locate, on her own, the Breast Cancer Resource Center in Austin.
- Infertility is an important issue for Suzanna, but both her primary care physician and her oncologist were very insensitive about this question. She is also very concerned about health insurance. She would like to change jobs, but she feels she must remain in her current job to avoid the risk of losing insurance coverage.

MS. HOLLY FAY

- Holly's son was diagnosed with testicular cancer last year, at age 22. She and her husband spent six months with him at their second home in Florida while he underwent treatment. He returned to Florida State University cancer-free in January, and his parents returned to Austin.

- Over the course of the spring semester, it became obvious to Holly that her son had emotional and psychological problems. She and her husband intervened, briefly placing him in a mental health facility and then spending the summer with him in Florida.
- Now back in school and doing well, Holly's son says that his problems began after his treatment was completed. During treatment, he was able to concentrate on the goal of recovering from cancer. The transition back to everyday life was difficult. Nevertheless, it was necessary for him to remain a full-time student to keep him enrolled in his parents' insurance plan.

MS. PEGGY LITTLE

- At the end of treatment, cancer patients should be placed in a formal one- or two-year postcancer program to receive guidance on survivorship, which should be covered routinely by health insurance. The program would provide screening, counseling, and step-by-step instructions in practical areas like nutrition. Each patient should receive written plans for long-term follow-up.
- In response, Dr. Kripke noted that long-term survivorship is still a relatively new phenomenon. In some areas, such as nutrition and exercise, not enough is known to make recommendations for all cancer survivors. Much research still needs to be done.
- Dr. Bleyer added that there are as many as 130 different types of cancer, each with different stages and treatment protocols. It may take years to develop routine standards of care for each type of cancer. Models being developed for the pediatric population may eventually be adaptable to other age groups. In the meantime, patients and their families can help by keeping track of everything that happens during treatment and follow-up.
- Dr. Bleyer also noted that depression or post-traumatic stress disorder following cancer is not uncommon, but is not often anticipated or addressed by physicians. Other common post-treatment problems include the Lazarus syndrome, in which patients feel guilt associated with surviving while others have died, and the Damocles syndrome, in which the possibility of recurrence hangs over the patient's head.

MR. CRAIG LUSTIG

- Without devoting adequate resources to the establishment of appropriate systems for collecting information, effective follow-up of cancer survivors will not be possible. This is a challenge for the cancer care community that is as important as the challenge of finding a cure.

MS. MONICA GAMBRAH

- Ten years ago, Monica went to the emergency room because she had a boil on her breast. The boil was aspirated, and she was told it was nothing. The next day, her primary care physician gave her the same response. She was told that she could not have a mammogram because it had only been six months since her previous one. Finally, after two months of delay, she insisted on having the boil removed, and a biopsy showed that she had breast cancer that had spread to her lymph nodes. Doctors should be better trained to listen to the concerns of patients and take each warning sign of cancer seriously.

MR. ERIC RODRIGUEZ

- Hope and motivation to survive are important factors in dealing with cancer. Within 24 hours of being diagnosed with brain cancer 11 years ago, Eric met a two-year-old boy who had already undergone neurosurgery five times. He was too young for radiation or chemotherapy, and his tumor continued to come back. Eric learned that the boy's mother had breast cancer and his father had recently died of cancer. Like many other cancer survivors, Eric was moved by this experience and motivated to return to the place where he received his treatment in order to help others.

MS. CRYSTAL GRIFFITH

- The M. D. Anderson Cancer Center made an effort to follow up with Crystal. They sent a questionnaire and made telephone calls to ask about her health and whether she had received follow-up examinations.

MS. ELISA GARCÍA

- Elisa was diagnosed with cervical cancer in June 2002, following the birth of her second child. Although she knows that an abundance of information is available, she finds the task of learning what to do next after surgery overwhelming and sometimes depressing.

MR. MATTHEW KRESBACH

- Matthew spoke on behalf of his friend Carl, who has stage IV pancreatic cancer. Diagnosed in 1999, Carl has survived much longer than the usual six months, but he has now exhausted virtually every treatment option available. He has participated in so many clinical trials he is no longer considered a reliable candidate for experimental therapies. Carl would feel that he has more control over his own life if compassionate use of experimental drugs was extended to patients with late-stage disease, even though the application of those therapies might not result in statistically useful information.

MR. MICHAEL LIN

- Michael is a two-year Hodgkin's lymphoma survivor. This meeting has reinforced his belief that survivors should be better integrated into programs to help other patients and survivors.

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

Dr. Leffall thanked Mr. Watson for his efforts as moderator and asked members of the Panel for their final remarks. Remarks from key NCI personnel in attendance were also solicited.

Dr. Rowland said that she was moved by the incredible human resilience reflected in the testimony presented during the meeting. As Director of the NCI Office of Cancer Survivorship (OCS), she is pleased that the Panel has chosen survivorship as the theme for its current series of meetings. She stressed the fact that survivors, family members, and care providers cannot succeed alone; it is the community that makes a difference. Dr. Rowland invited everyone to visit the OCS Web site at survivorship.cancer.gov.

Dr. von Eschenbach spoke not as Director of the NCI, but as a cancer survivor. He was diagnosed with melanoma in 1989 and three years ago, was diagnosed with prostate cancer. Recently, he learned that a

scratch on his nose that would not heal is a basal cell carcinoma and will have to be removed. The message he heard from today's testimony is that cancer is no longer a death sentence as it was years ago. When he began his career in the 1980s, there were three million cancer survivors; now there are almost ten million. This means that many more people are living with the aftermath of cancer. A systems solution is required to deal with this situation. No single Federal agency has all of the resources and expertise to address this problem. The problem also has political, economic, social, and cultural components. Much of the information needed to address these issues will have to come from survivors—the people who best understand the scope of the problem.

Dr. Kripke thanked the speakers for their courage and their willingness to share often-painful stories. She noted that 30 or 40 years ago, such a meeting would not have been possible, because there were so few survivors. The fact that we do not yet know enough about survivorship makes it especially important for survivors to describe their experiences in dealing with the long-term effects of cancer and its treatment. A number of common themes have become apparent in the meetings held so far in the series on survivorship, including anxiety about late effects of treatment, difficulties with medical insurance, employment discrimination, the financial burden caused by cancer treatment, and—on the positive side—the way survivorship has changed lives and made people stronger. Differences between age groups have also been illustrated through testimony heard at these meetings. Adolescents and young adults have been described as “the lost cohort,” less likely to participate in clinical trials than other age groups and less likely to be followed over time. Cancer in this age group is also uniquely devastating because patients are just beginning their independent lives; they are especially focused on returning to a normal life and establishing relationships. Messages from these meetings include the need for more-specific and less-toxic cancer treatments; more and better information for patients, their families, and primary care providers; and grassroots support to help people through the transition from treatment to life as a survivor.

Mr. Armstrong noted that even though survivorship is defined as a process that begins at diagnosis, most people diagnosed with cancer do not immediately think of long-term survivorship, but rather about what will happen in the short term and whether they will survive at all. The question of what to do as a long-term survivor comes up after a patient has endured the treatment process. This is a relatively new question, and we are fortunate that more and more people are able to ask it. He cited his own treatment as a success story in terms of focusing on long-term effects of treatment. His doctors had started him on a protocol using the drug bleomycin, but when they realized the effect this would have on his lungs, they switched him to a different protocol. Lance did not understand the significance of this change at the time, but had it not been made, he would never have been able to race competitively again. The new protocol required him to receive treatment as an inpatient rather than as an outpatient, but for him, it was worth the trouble. In the future, some of the issues raised at this meeting—e.g., about fertility and other problems caused by radiation—may also be resolved.

Dr. Leffall thanked all of the speakers and NCI staff and expressed particular gratitude to the Lance Armstrong Foundation for its help in making arrangements for the meeting.

CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President's Cancer Panel meeting, *Living Beyond Cancer: Challenges for Adolescent and Young Adult Cancer Survivors*, held September 22, 2003, is accurate and complete.

Certified by:

Date:

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