

# MEETING SUMMARY PRESIDENT'S CANCER PANEL

## LIVING BEYOND CANCER: SURVIVORSHIP ISSUES AND CHALLENGES AMONG PEDIATRIC CANCER SURVIVORS

September 5, 2003  
Denver, CO

### OVERVIEW

The purpose of the meeting was to examine challenges of living after diagnosis and treatment of pediatric 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) sought input to help develop recommendations on issues of survivorship to the President of the United States, the Secretary of Health and Human Services (HHS), Congress, and the broader community of researchers, policy makers, advocates, and others.

### PARTICIPANTS

#### *President's Cancer Panel*

LaSalle D. Leffall, Jr., M.D.  
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 von Eschenbach, M.D., Director, NCI

#### *National Cancer Policy Board*

Joseph Simone, M.D.

#### *Speakers*

Malcolm Brewster, Community Representative, Maryland  
Alfredo Cerritos, Community Representative, Maryland  
Adam Cox, Community Representative, North Carolina  
Pam Cox, Community Representative, North Carolina  
Aileen Delgado, Community Representative, Pennsylvania  
Michael DiLorenzo, Community Representative, Pennsylvania  
Danielle Eichner, Community Representative, Maryland  
Marilyn Eichner, Community Representative, Maryland  
Angie Farfan, Community Representative, Missouri  
Devarda Jones, Community Representative, Maryland  
Coreen Oshiro, Community Representative, California  
Karen Oshiro, Community Representative, California  
Daniel Sieck, Community Representative, Maryland  
Catherine Woodman, M.D. (for Ethan Kline), Community Representative, Iowa

## **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.

## **PRESENTATION OF THE NATIONAL CANCER POLICY BOARD ON CHILDHOOD CANCER SURVIVORSHIP—DR. JOSEPH SIMONE**

### **Background**

Dr. Simone is Co-Chairman of the National Cancer Policy Board (NCPB, the Board), a component of the National Academy of Sciences' Institute of Medicine (IOM) that has published several reports on the quality of cancer care. Dr. Simone has been a pediatric oncologist since 1963 and has witnessed drastic changes in the outcomes of treatment of children with cancer. He presented an overview of findings in the NCPB report entitled *Childhood Cancer Survivorship: Improving Care and Quality of Life*. This is the first comprehensive report on survivorship relating to childhood cancer, defined as cancer in patients under the age of 20.

### **Key Points**

- In 1997, there were an estimated 270,000 survivors of childhood cancer in the United States, of whom 175,000 were under 20. This represents 1 in 810 individuals under 20 and 1 in 640 between the ages of 20 and 39. The number is probably substantially larger today.
- Late effects of cancer include second cancers; neuropsychological effects from radiation and chemotherapy; psychosocial effects; denial of insurance; body image problems; and family disintegration. About two-thirds of children with cancer experience at least one late effect, and about one-fourth experience serious late effects (effects that are life-threatening or that limit activities of daily life). Late effects can appear soon after therapy or many years later.
- Some late effects are preventable through dose reduction or substitution of less toxic agents. The impact of late effects can be mitigated through early intervention, such as the use of alternative teaching methods to reduce the seriousness of learning disorders caused by radiation. The key to reducing the severity of late effects is close follow-up.
- The NCPB found that there are no generally accepted guidelines for follow-up care. The Board recommends development of evidence-based, tumor-specific clinical practice guidelines for the care of childhood cancer survivors. The NCI-supported Children's Oncology Group (COG) has reported that it is close to completing a set of guidelines. (The majority of children participating in clinical trials are treated in institutions that are members of COG.)
- There are also no widely accepted systems of follow-up care. Guidelines are needed on how to structure follow-up care and to determine who should administer various tests (e.g., pediatric oncologists, primary care physicians, nurse practitioners, etc.). Without systematic follow-up, patients are "lost" when their families move or they are transferred to different institutions. Follow-up is often stopped when patients seem to be doing well. The NCPB recommends defining a set of standards for follow-up care linking primary and specialty caregivers for the long term. All treating institutions should have a plan of care that is appropriate to the stage of follow-up.

- Alternative models of care delivery should be evaluated. A new specialty in survivorship may be emerging. The nursing field may be interested in developing a new model for providing follow-up care.
- A majority of cancer survivors are unaware of their risk for late effects. The medical community, and especially COG, should work to improve awareness of late effects, their implications for long-term health, and the need for follow-up care of childhood cancer survivors.
- The NCPB found that there are not enough advanced practice nurses to staff follow-up clinics. Lack of adequate reimbursement for their services is a key issue.
- One in 300 ambulatory care visits by children in the United States is cancer-related. Primary care physicians are not well informed about pediatric cancer survivorship. However, the NCPB does not feel that this problem calls for additions to medical school curricula. Instead, it is suggested that professional education and training in this area be provided through professional societies, residency programs, the NCI Web site, oncology training and exams, and interdisciplinary meetings. In addition, each patient should have access to a standard set of guidelines that can be presented to a new doctor to explain the care that that patient needs.
- Many problems of cancer survivors are shared by children and adults with other chronic diseases. Services available for patients with other conditions could be useful to cancer survivors but are not used because of poor coordination among programs and agencies such as the Department of Health and Human Services (DHHS) and the Department of Education. The Board recommends additional support to the Health Resources and Services Administration (HRSA) to focus on childhood cancer survivors as it strives to implement *Healthy People 2010* goals for children with special needs.
- Many insurers do not cover the costs of care for childhood cancer survivors. In addition to insurance reform, the Board recommends broadening “safety net” programs such as HRSA’s Community and Migrant Health Centers to include childhood cancer survivorship.
- To support research on treatment of late effects, the Board recommends systematic follow-up of large cohorts of survivors to reveal the extent of late effects and suggest preventive and ameliorative strategies. Several members of COG are actively participating in the Children’s Cancer Survivor Study, but many academic centers do not view research on late effects as important.
- The NCI can play a major role in this effort through its Web site and its Office of Cancer Survivorship (OCS). The Board recommends that the NCI take responsibility for coordination of survivorship activities among the various Government agencies involved.

## **DISCUSSION—DR. SIMONE**

### **Key Points**

- The NCPB report will be presented to various professional societies and in a planned briefing on Capitol Hill. The report will also provide survivorship organizations with supporting evidence from an independent, unbiased body indicating that specific actions are needed.
- Asked whether this report addresses the influence of the health care system on cancer survivorship, especially in terms of access to care and insurance coverage, Dr. Simone explained that this topic was addressed in a previous report, entitled *Ensuring Quality of Cancer Care*, which focused on cancer care in general rather than specifically on pediatric cancer.

- Mr. Armstrong suggested providing follow-up care in specialized facilities separate from the institutions where children receive their initial treatment; this approach would create a different environment that might be less stressful than revisiting places where unpleasant experiences occurred. He added that the existence of separate facilities would encourage survivors to return to the clinical setting and help others with similar experiences. A model could be established in an urban setting, where the numbers of childhood cancer survivors are high enough to justify a separate facility.
- Julia Rowland, Director of the NCI OCS, noted that about two dozen pediatric follow-up clinics have been identified, and the NCI has met with their directors to learn about their structure and services. Some are located within treatment institutions, and some are in outlying centers or affiliated facilities. Some provide services to individuals who were not treated at the institutions that operate the clinics. These clinics have not yet examined outcomes, and the best service delivery system for delivering follow-up services has yet to be identified. Providing the evidence base for such a system is a challenge for the NCI and the research community.
- In addition to professional training in survivorship, education should be provided to children to help develop healthy behaviors.
- Ms. Diane Traynor, of the Pediatric Survivorship Foundation, reported that her organization provides information on late effects to patients after they leave treatment facilities. She expressed support for COG's efforts to establish follow-up procedures that can be passed along as patients are transitioned into community-based care.
- Advocacy groups such as the National Coalition for Cancer Survivorship (NCCS) play an important role in raising awareness of these issues through their outreach efforts.
- To help cancer survivors understand their long-term needs and risks, they should be provided with concise summaries of their diagnoses and treatment. A format should be developed to provide this information for patients currently in treatment. Adults who were treated for cancer as children should be given a form that can be submitted to the institutions that treated them in order to collect this information. The Lance Armstrong Foundation is developing templates for this type of information collection and has found that oncology nurses and advanced practice nurses are valuable partners in this effort.
- The capabilities of cancer registries could be expanded to collect treatment information, along with incidence and mortality data, not only for children treated in major cancer centers but also those treated outside that system. Additional financial resources would have to be provided to make this possible.
- Approximately three-quarters of children with cancer under the age of 10 are enrolled in clinical trials; of the population up to age 20, the proportion is about 50 percent. This is still high compared with the 2 or 3 percent of adults with cancer who enter trials. One reason is the relatively small number of pediatric cancer cases, which represent less than 1 percent of all cancer cases. Most children with cancer go directly to a specialized center and are treated by a pediatric oncologist with an organized plan of care, whereas adults are referred serially—from primary care doctor to surgeon to radiologist to radiation oncologist to medical oncologist—with little or no coordination of care.

## **STORIES FROM SURVIVORS—GROUP I**

### **Presenters**

**Ms. Pam Cox**  
**Mr. Adam Cox**  
**Ms. Angie Farfan**  
**Ms. Karen Oshiro**  
**Ms. Coreen Oshiro**

### **MS. PAM COX AND MR. ADAM COX**

#### **Background**

Adam, who is 20, was diagnosed with a grade II oligodendroglioma brain lesion in 1986, when he was 3 years old. Following surgery that removed only part of the tumor, he received radiation treatments. Adam still has his tumor and sees a neurologist every 6 months. He receives medication to control headaches and prevent seizures. While in school, Adam was treated with Ritalin to help improve his ability to concentrate; he is now receiving Concerta for the same purpose. Adam was introduced by his mother, Pam.

#### **Key Points**

- Adam's treatment with full-brain radiation at an early age resulted in learning disabilities, poor short-term memory, and problems with concentration. His biggest deficit is in organizational skills: he is unable to manage money and has a limited understanding of the concept of time. Adam lives next door to his mother, which allows him a sense of independence, but Pam makes sure he takes his medications and accompanies him on shopping trips.
- Adam has tried to obtain a General Equivalency Diploma (GED) but has not been able to pass the math test. He did well in special classes, but the test is based on material taught to regular classes.
- Adam wants to be a productive member of society, but it is extremely difficult for him to find and hold a job. Potential employers have been unwilling to accommodate Adam. He has demonstrated that he can bag groceries, but the store where he applied for a job also wanted him to operate a cash register, which he is unable to do.
- After several months, Pam was able to get Adam qualified to receive Social Security benefits. She knows he could not have navigated that system alone, and she worries about what would happen to him if she and his father were not available to help him. Applying for food stamps was a particularly humiliating experience. After 6 weeks of filing paperwork, he was approved for \$10.00 per month.
- Pam is grateful to the Pediatric Brain Tumor Foundation and other groups that have helped Adam. In general, however, she is frustrated that the problems of cancer survivors are so often overlooked. People think that if a person has survived the disease, everything is fine.

### **MS. ANGIE FARFAN**

#### **Background**

Angie is a 30-year-old Ewing's sarcoma survivor. She was 4 years old when first diagnosed, and she received radiation therapy followed by 2 years of chemotherapy. She remained healthy until age 10, when

a tumor was found in her left femur; doctors performed a hip disarticulation (amputation), which was followed by 2 more years of chemotherapy. When she was 14, a tumor found in her lung was treated with surgery and more chemotherapy.

## **Key Points**

- Although she learned a great deal about herself as she fought cancer, Angie says she has learned more about herself since she has been “cancer free,” a term she feels is misleading because the effects of having had cancer become a significant part of a survivor’s life.
- Because she worried that no one would want to spend his future with a cancer survivor with one leg, Angie “settled” for marriage to a man she did not love simply because he accepted her. She ignored the problems in her marriage, attributing them to her own issues as a cancer survivor.
- The institutions that treated her cancer did not prepare Angie for the treatment-related complications she was to encounter when she became pregnant, but her friendship with an oncology nurse led her to seek the information she needed. She spent the last 4 months of her pregnancy in the hospital, and her son was born in the cardiac intensive care unit. Following his birth, she was diagnosed with congestive heart failure. Angie was never afraid of dying until she became a mother; although weary of fighting one crisis after another, she faced this one for her son. Today he is 5 years old, and her heart has regained normal functioning.
- Angie is followed by a pulmonologist, a cardiologist, a gynecologist, a prosthetist, and an oncologist. She finds it overwhelming and confusing to be the sole coordinator of her own care. Each time she faces a normal medical issue, such as kidney stones, she must educate new specialists about her issues.
- After struggling through a divorce, Angie is now preparing to marry again. She has obtained a master’s degree and has a successful teaching career.

## **MS. KAREN OSHIRO AND MS. COREEN OSHIRO**

### **Background**

When Coreen was diagnosed at age 2 with soft tissue cancer, she received radiation therapy. She was healthy until age 12, when she was diagnosed with a secondary bone cancer that may have been caused by the initial radiation. The cancer was so aggressive that, after chemotherapy and radiation, she underwent a hemipelvectomy. Her treatment ended in 1994. She receives physical therapy for scoliosis and has to be fitted for a prosthesis every 2 years. Coreen was introduced by her mother, Karen.

### **Key Points**

- Like many young children with cancer, Coreen did not know much about her earliest diagnosis and treatment—but she knew she was “different.”
- During her second experience with cancer treatment, her family struggled to maintain her education as she went back and forth between home and inpatient facilities. Her eventual return to school was easier than it might have been because her medical team visited her class and explained her situation to her classmates. She continued to require frequent medical attention for unexplained but chronic problems caused by her cancer treatment, and her school was reluctant to provide special services because her cancer treatment had ended.

- Coreen is now enrolled in a college near Los Angeles, chosen for its proximity to the centralized services available in that city. Her medical team in Honolulu provided her with a booklet summarizing her treatment history, and she used this information to take charge of her care by building a new medical team in Southern California. Because her social worker was not able to help her locate resources for long-term care, she has had to negotiate access to these services herself. Obtaining a prosthesis has been a problem due to the difficulty of finding a prosthetist with the necessary specialized expertise who is covered by her health insurance.
- College life has presented a new set of barriers to overcome, including physical accessibility and frequent absences for physical therapy. Coreen has found helpful resources within the college to help address these issues.
- Survivorship, Coreen believes, is a transition with many phases.

## **DISCUSSION—MS. COX, MR. COX, MS. FARFAN, MS. K. OSHIRO, MS. C. OSHIRO**

### **Key Points**

- Keeping children in school during their cancer treatment provides an opportunity to raise the level of awareness of issues related to pediatric cancer survivorship. However, many school systems are not well prepared to accommodate the needs of children with special needs associated with cancer treatment and its effects.
- Many children who undergo cancer treatment are unaware that they are involved in clinical trials, and their families often do not fully understand trial participation. Although enrollment is usually mentioned at the time of diagnosis, it should also be discussed later, after patients and families have had time to absorb the emotional impact of diagnosis. Families should be provided with written descriptions of the trials in which children participate as part of a medical history that can be used to inform long-term care.
- Some insurance companies pay for a first prosthesis but fail to cover new prostheses, articles of clothing needed to accommodate them, or prosthesis maintenance as children grow.
- Ms. Dianne Traynor, of the Pediatric Survivorship Foundation, suggested that because there is so much discrimination against pediatric cancer patients and their families, childhood cancer survivors should be identified as a *minority group* and be provided with the same types of assistance other minority groups receive.
- Few studies have looked at discrimination against various populations of cancer patients, but it would be logical to assume that these groups experience the same discrimination faced by minorities in the general population.
- Survivors of childhood cancer have always met with both subtle and overt forms of discrimination, including availability of special services in school and access to employment. The most effective approach to addressing this issue is empowering families with information about treatment, its effects, the kinds of social and economic barriers that can be expected, and available resources.
- Since its inception in 1986, the NCCS has worked to eliminate discrimination in employment and insurance coverage and lobbied for the classification of cancer patients and survivors as individuals with disabilities.
- It is important to make sure that children with cancer have an opportunity to “be children.” Playing can help distract children from the rigors of cancer treatment and help them feel “normal.” Similarly,

including children with cancer in everyday family activities, such as assigning them routine chores, reduces their sense of being different.

- The amount of family support received by childhood cancer survivors depends largely on the family structure before diagnosis. Function and dysfunction alike are magnified by the cancer experience. Some marriages cannot survive the stress associated with childhood cancer.
- Many cancer survivors share the experience of being expected to have no problems following treatment; most people see cancer as an “on or off” situation and are unaware of survivors’ long-term emotional, psychosocial, economic, and family problems. However, research and health care systems are gradually being changed to address these issues.

## **STORIES FROM SURVIVORS—GROUP II**

### **Presenters**

**Mr. Michael DiLorenzo**

**Ms. Aileen Delgado**

**Dr. Catherine Woodman (for Mr. Ethan Kline)**

### **MR. MICHAEL DiLORENZO**

#### **Background**

Michael, a 32-year-old non-Hodgkin’s lymphoma survivor, was diagnosed with cancer when he was 6 years old and finished his chemotherapy, paraspinal surgery, and radiation treatment at the age of 7. He has been in remission for 25 years but has had several major surgeries related to treatment side effects.

#### **Key Points**

- Michael’s transition from the care of a pediatric oncologist at the Children’s Hospital of Philadelphia (CHOP) to an internist at the University of Pennsylvania when he was in his early twenties was relatively smooth. Just prior to that transition, he became involved in a CHOP long-term survivor study, and he is currently involved in a long-term follow-up study conducted by the University of Minnesota. Information provided through that study has been a great help to him.
- Throughout his treatment, and especially through his participation in the long-term survivorship studies, Michael was able to stay informed about his diagnosis, treatment, late treatment effects, and needed follow-up care. It was difficult to find a local cardiologist who was familiar with the special needs of someone experiencing the side effects of radiation treatment, but he now has a qualified practice group; however, he has decided to travel to the University of Pennsylvania for most of his primary care because he has been unable to find a local doctor with resources as complete as those available in the university setting.
- Michael feels that because he has been a cancer patient or survivor as long as he can remember, he has experienced fewer psychosocial issues than an adult whose life is suddenly interrupted by a cancer diagnosis. He has always had a matter-of-fact attitude toward his health problems.
- Michael was supported by a very close family and network of friends. His transition back to school after treatment, he feels, was easier than that experienced by some others because his Catholic school was small and students received extensive one-on-one attention. Teachers from his school attended seminars at CHOP on dealing with sick children.

- Cancer patients and survivors should not have to rely on physicians for information about late effects of cancer treatment, especially since some doctors are less knowledgeable than others. There should be a central location where patients and their families can obtain up-to-date information on cancer treatments and their late effects. Continuing medical education on these issues should be offered to physicians and nurses.

## **MS. AILEEN DELGADO**

### **Background**

When Aileen, now a junior in college, was diagnosed with leukemia at the age of 8, she was treated with chemotherapy and radiation. She received a bone marrow transplant from her younger sister following a relapse in 1990, and another 2 years later. She has been in remission for the past 14 years.

### **Key Points**

- Aileen, who was born in the Dominican Republic, was in the United States on vacation when she was diagnosed with leukemia. As a result of this diagnosis, her mother decided to remain here. Language barriers made it difficult to understand much of what they were told about Aileen's diagnosis and treatment.
- Chemotherapy and full-body radiation have led to long-term problems, including scoliosis, that Aileen and her mother were never told might happen. She was also not informed until recently about the possibility that radiation could cause infertility; she is currently being treated in the hope that she will someday be able to have a family.
- Aileen is concerned about the negative things often said to cancer patients. During her relapses, Aileen was often told that her chance of surviving past the age of 15 was not great. It took several years for her to realize that some people do survive cancer.
- Aileen regrets having missed much of the childhood experiences that her sister enjoyed. Cancer made her grow up quickly. Her experience in public schools was difficult because other children did not understand why she was so different. She missed a year of school due to radiation treatments.
- As a college student, Aileen has friends who know that she had cancer in the past but are unconcerned about it because they are unaware of the long-term effects she experiences; this is fine with Aileen because she prefers not to be reminded of her problems or to be treated as if she is fragile or strange. However, Aileen wants to increase awareness about cancer survivorship on her campus and hopes to start an organization or foundation to educate other students and share information with other survivors.

## **DR. CATHERINE WOODMAN for MR. ETHAN KLINE**

### **Background**

Ethan was diagnosed with a medulloblastoma 3 years ago, at the age of 5. He was treated with surgery to reduce the size of the tumor, as well as radiation and 48 weeks of chemotherapy. His last treatment was September 11, 2001. His treatment has had numerous physical and neuropsychiatric effects, including hypothyroidism, growth hormone deficiency, adrenal insufficiency, hearing loss, and problems with coordination and dexterity. Dr. Woodman is Ethan's mother.

## Key Points

- Even though Ethan's neuropsychological profile indicates problems in visual, spatial, fine motor, information acquisition, and social skills, his school has identified him as a normal child, and special services have been difficult to obtain. His parents and three siblings have provided him with tutoring in reading, spelling, writing, and keyboarding.
- Ethan is at risk for skin cancer, infertility, and psychological sequelae. He has experienced some sadness and anxiety as a result of his cancer experience.
- When Ethan's treatment ended in 2001, no one told his parents they were trading an acute illness for a group of chronic illnesses. Rather than continuing the team approach from treatment through survivorship, his doctors have simply monitored Ethan through quarterly checkups. His parents have been left with the responsibility for coordinating his care as a survivor. They had to persuade his pediatrician to perform screening tests because of his risk for endocrine abnormalities.
- During Ethan's treatment, it became difficult for his parents to find time for each other and their other children. However, since treatment has ended, the experience has made the family stronger.
- The most difficult aspect of survivorship is the unknown. The medical literature was not very helpful in dealing with Ethan's hearing loss. Less than 3 percent of the literature on pediatric cancer addresses late effects.
- Large cohort studies should be launched to follow children for life in order to learn as much as possible about long-term effects of pediatric cancer and its treatment.

## DISCUSSION—MR. DILORENZO, MS. DELGADO, DR. WOODMAN

### Key Points

- Although cancer remains stereotyped and stigmatized in much of Europe, the word *survivor* is widely embraced in the United States because it is an empowering concept that suggests the ability to provide inspiration and education to cancer patients and the general public. The word *victim* is seldom heard nowadays. The word *survivor* also serves as a reminder that former cancer patients are not really free of the effects of cancer treatment and should remain aware of possible problems as they age. Nevertheless, many survivors are still reluctant to talk about cancer in certain situations for fear of discrimination.
- Support for home schooling for children with cancer varies among communities. In some cases, teachers in the local school system volunteer their services, and some hospitals provide tutoring. Assistance with educational needs is often more difficult to obtain after treatment has ended.
- Emergency room personnel lack protocols for addressing the needs of cancer patients. Their ability to help such patients would be improved if patients were provided with brief summaries of their medical status and special needs to carry with them.
- Relationships with the opposite sex—particularly in relation to fertility—are profoundly affected by survivorship. Some speakers expressed that potential partners should be told early in a relationship that long-term effects of cancer treatment may occur at any time.
- The impact of pediatric cancer on siblings has recently become a focus for advocacy groups.

- Complementary and alternative practices, often supported by the fundraising efforts of volunteers, are made available by some pediatric clinics and hospitals but are not widely available after treatment because they are not covered by insurance policies. Complementary and alternative practices include not only alternative medical treatments but also massage therapy, acupuncture, music therapy, meditation, and other activities that can affect response to surgery and general wellness. Traditional therapy focuses on the tumor, but a more holistic approach includes attention to factors related to the “host,” or the person with cancer. The NCI supports research designed to develop scientific evidence of the efficacy of complementary and alternative treatments. Patients should talk to their doctors when considering such treatments because some substances should not be taken by patients undergoing chemotherapy. Alternative medicine should be considered only as a supplement to, and not a substitute for, standard, evidence-based therapy.
- Long-term follow-up care for pediatric cancer patients should be planned in the oncology setting and coordinated by advanced practice nurses, physician assistants, or “cancer guides.” Since children become adults and transition to the adult health care system, primary care physicians, emergency medical personnel, dentists, and others in that system must also be educated about the needs of cancer survivors. Survivors must also play a major role in coordinating follow-up care.

## **NCI DIRECTOR’S REPORT— DR. ANDREW C. von ESCHENBACH**

- Dr. von Eschenbach called attention to several events that took place in 1971: he began his career as a medical oncologist; the National Cancer Act was passed; and Lance Armstrong was born. In the 1970s, 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 cancer so completely that he was able to win the Tour de France five times.
- Dr. von Eschenbach described recent advances in detecting and treating cancer as “progress with a price”; improved survivorship means an increase in the number of people experiencing late effects of cancer and its treatment. Scientists have not devoted much attention to what survivorship entails for cancer patients. Today, while fundamental knowledge about cancer continues to expand, the NCI has turned its attention to the consequences of cancer and its treatment and envisions a future in which everyone with cancer can be a survivor. Based on the tremendous progress that has been made, 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 the disease so that patients can live with cancer.
- The NCI is listening to the stories of cancer survivors presented in testimony at PCP meetings and is developing a research portfolio on cancer survivorship that will be informed in part by such testimony. The time and effort devoted by patients and their families to providing their insights into the problems and needs of cancer survivors will help shape a future in which all cancer patients have the opportunity for fulfillment in spite of having been diagnosed with and treated for cancer.

## **STORIES FROM SURVIVORS—GROUP III**

### **Presenters**

**Mr. Malcolm Brewster**

**Ms. Devarda Jones**

**Mr. Alfredo Cerritos**

**Ms. Danielle Eichner**

**Mr. Tom Eichner**

**Mr. Daniel Sieck**

### **MR. MALCOLM BREWSTER AND MS. DEVARDA JONES**

#### **Background**

Malcolm, a 16-year-old high school student, was 9 years old when he was diagnosed with a nonmalignant brain tumor. He had surgery to partially remove the tumor and 6 weeks of radiation to eradicate the remainder. Because his pituitary was affected, he has been taking growth hormones. He has trouble with reading and receives tutoring in math. Ms. Jones is Malcolm's mother.

#### **Key Points**

- Although his treatment was difficult, the most challenging part of Malcolm's cancer experience has been the physical and emotional effects of the disease. Throughout his recovery, his stamina has been significantly reduced. His parents, stepfather, grandparents, godparents, cousins, and teachers have all provided support in helping him keep up with his schoolwork. His mother is his organizer and scheduler, making sure Malcolm's pediatrician has been kept up to date on his treatment, giving him injections of growth hormones, and coordinating repeated visits with endocrinologists and others involved in his follow-up care.
- The family has tried alternative and complementary therapies to help Malcolm deal with the residual effects of radiation therapy. They have worked with a homeopathic doctor and made dietary changes.
- A social worker provided by Georgetown University Hospital connected the family with a range of local and national services, including Internet-based resources and foundations. Malcolm's neurosurgeon was very sensitive to his emotional needs and took his questions seriously.
- Art therapy provided by the university has helped Malcolm work through his feelings. He has used drawing and sculpture to express his understanding of cancer and his anger, fear, and confusion. He also uses art to express positive images of fearlessness and strength. Malcolm presented slides of some of his artwork.
- His family's fear of radiation treatment was based on stories they had heard indicating that he would be affected cognitively. His mother did as much research as she could on the subject. She obtained second and third opinions before deciding that radiation was the best choice.
- Malcolm volunteers at Camp Fantastic, operated by Special Love in Front Royal, Virginia, to help other children who have similar physical and emotional problems enjoy life as normal kids. The only discrimination he has faced has been in a support group, where the mother of a child with a malignant tumor said that Malcolm did not belong because his tumor was benign.

## **MR. ALFREDO CERRITOS**

### **Background**

Alfredo was born in Mexico City in 1982 and moved to the United States with his family at the age of 7. He was diagnosed with leukemia shortly before his ninth birthday and finished his treatment in 1996. Chemotherapy and radiation inhibited his growth and caused learning disabilities.

### **Key Points**

- During Alfredo's cancer treatment, communication was difficult because his mother did not speak much English and the Spanish interpreters made available by the hospital did not know much about cancer and were not familiar with medical terminology. Sometimes, Alfredo had to serve as interpreter, which was difficult when he was lying in bed half awake. Interpreters serving in pediatric oncology facilities should have better training in cancer and its treatment.
- Alfredo feels that during his treatment, his parents experienced depression that went unnoticed. He wishes that someone had been available to talk to them. His siblings and classmates treated him as if he were fragile; he was excluded from group activities even when his strength began to return. He feels that this enforced isolation encouraged other children to tease him.
- Alfredo takes longer to grasp new material than other students in his college classes. However, his doctors have not been able to determine the extent to which his abilities have been affected by his treatment, so his school does not allow him the same accommodations as other students with disabilities.
- Alfredo's family was greatly helped by volunteer organizations such as Special Love. They provided an environment in which he was not considered different or excluded from normal activities. Through a program for siblings of pediatric cancer patients, his brothers and sister were able to deal with their fear of cancer.

## **MS. DANIELLE EICHNER AND MS. MARILYN EICHNER**

### **Background**

Danielle was diagnosed with leukemia in 1996, at the age of 11. An aggressive course of radiation and chemotherapy resulted in remission after 7 days, but her treatment was a harrowing process. Her mother, Marilyn Eichner, feels that these procedures were instrumental in causing Danielle's small size, delayed puberty, respiratory problems, and cognitive deficits.

### **Key Points**

- One of the biggest problems Danielle faced during her treatment was education. She missed attending school in the seventh and eighth grades. The tutor provided by the Home and Hospital program where she was treated was not sufficient; her family located a tutor who joined the Home and Hospital program so that part of her compensation could be covered by insurance. Although Danielle passed those grades, she did not learn as much as students who attended class, and she has had problems with math in high school and college.
- Danielle recommends using new technologies, such as videoconferencing, to help pediatric cancer patients more fully participate in mainstream educational activities. Teachers should be educated about the long-term effects of cancer treatment.

- Because Danielle needed someone to be with her during treatment, her mother went from full-time to part-time employment, not only reducing the family’s income but also depleting savings. The Family and Medical Leave Act protected their jobs, but not their income. The family had not been prepared to consider this issue when Danielle’s cancer was diagnosed.
- The siblings of cancer patients are often left with unanswered questions and a feeling that they are less important than the sick child.
- Social workers are very good about answering questions and finding solutions to specific problems that are brought to their attention. However, Danielle feels that families should be given a “road map” of potential problems and possible ways to solve them.
- The family’s managed care organization considers Danielle “cured” after treatment and provides very limited coverage for follow-up care. It is difficult to prove that certain medical conditions are late effects of cancer treatment. Survivors of pediatric cancer need multidisciplinary late-effects clinics that are separate from pediatric oncology clinics. These clinics would screen children, help carry out follow-up plans provided by oncologists, educate families about late effects, and provide access to appropriate resources.

## **MR. DANIEL SIECK**

### **Background**

Daniel was diagnosed with acute lymphoblastic leukemia (ALL) when he was 11 years old and received chemotherapy for 6 months. He was in remission until age 15, when he relapsed and underwent intensive radiation therapy and a bone marrow transplant. Daniel has health concerns relating to his cancer treatment. He has a weakened heart, high blood pressure, and avascular necrosis in his knees.

### **Key Points**

- After he completed his first course of treatment, Daniel returned to middle school with his life relatively unchanged, and he did not want to be involved in cancer-related camps or organizations. After his relapse in 1995, however, cancer became a permanent part of his life.
- During treatment, Daniel was home-schooled by his mother, who is a teacher, because he spent his entire freshman year of high school in the hospital. He enjoyed returning to school as a sophomore but missed participating in sports as he had before his relapse. During his senior year, he experienced depression for the first time, and his grades began to suffer. After having the same problems in his freshman year at college, he returned home to confront emotional issues that had been left unaddressed. He worked with a psychiatrist to cope with these late psychological effects of his cancer experience and has now resumed his college education.
- Daniel feels he was given fair warning that he was at risk for the avascular necrosis that affects his knees—a result of the use of steroids to treat pneumonia associated with his bone marrow transplant. However, he was not prepared for other late effects he has experienced or for others that may appear in the future. A national source of information on the probable effects of standard treatments would be useful to all cancer patients.

## **DISCUSSION—MR. BREWSTER, MS. JONES, MR. CERRITOS, MS. D. EICHNER, MS. M. EICHNER, MR. SIECK**

### **Key Points**

- Many cancer survivors share the opinion that positive outcomes have resulted from their cancer-related experiences, including close friendships with caregivers and others they have met during treatment, discovery of new perspectives on life, development of maturity beyond that of their peers, a sense of accomplishment at having found the strength to overcome the obstacles they have faced, and the opportunity to share experiences and insights at meetings like this.
- Camps such as those operated by Special Love make it possible for children with cancer to experience typical camp activities—from swimming to craft classes to campfires—while receiving medications and even chemotherapy. These types of activities are made feasible by the fact that NIH has provided protocols that permit patients on active treatment to participate.

## **CLOSING REMARKS—DR. LEFFALL**

### **Key Points**

- Many of the speakers have emphasized the value of “late effect” clinics for pediatric cancer survivors. Treatment is not the entirety of cancer care, but simply the first phase.
- Financial issues are important, not only in terms of payment for medical treatment, but also for the care and support of the entire family.
- The role of friendship in cancer survivorship cannot be overstated. Many survivors have reported that the friendships they developed with their caregivers have made their experiences much easier to endure.

## **TOWN HALL MEETING—CHALLENGES AND ISSUES OF CANCER SURVIVORS SEPTEMBER 5, 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, was also in attendance. The meeting was moderated by Mr. Wellington Webb, former Mayor, Denver, Colorado, and a cancer survivor.

### **INTRODUCTION—DR. LEFFALL**

- Dr. Leffall introduced members of the President's Cancer Panel and Mr. Wellington Webb.

### **OPENING REMARKS—MR. WEBB**

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

### **MR. SEAN SWARNER, DENVER, CO**

- When Sean was diagnosed with stage 4 Hodgkin's disease in 1988 at the age of 13, he was given approximately 3 months to live. His cancer went into remission following 6 months of treatment. Eighteen months later, though, he was diagnosed with Askin's disease, a very aggressive tumor that affects only three in one million people. After removal of a golf ball-sized tumor attached to his lung, Sean was expected to live about 2 weeks.
- Today, 28-year-old Sean is reportedly the only person to have had both Hodgkin's disease and Askin's disease and the longest-living survivor of Askin's disease. After college, which included active participation in track-and-field events, he was accepted into a doctoral program in psychology.
- At this point, he felt he wanted to do something for other cancer patients, but he knew that providing psychological counseling would be too emotional for him. When he learned that no cancer survivor had ever climbed Mount Everest, he took on that challenge, which he accomplished last year.
- Sean and his brother founded the Cancer Climbers Association, which raises cancer research funds by sponsoring mountain climbing, bungee jumping, skydiving, white-water rafting, and camping programs. The Association plans to send cancer survivors to the top of the highest mountain on each continent and to the North and South Poles.
- Sean feels that his cancer experience did not make him who he is, but it did help him become who he is. When he reflected on his experience after it was over, he realized that it would have been helpful if information on long-term psychological effects of cancer diagnosis and treatment had been provided along the way.

## **MR. RALPH VARELA, DENVER, CO**

- Ralph experienced frequent incidents of unbearable abdominal pain for 6 years before he was diagnosed with pancreatic cancer. His doctor told him he had a choice of undergoing the Whipple procedure (surgical removal of his tumor and part of his pancreas) or spending his estimated 6-month life expectancy putting his affairs in order. Ralph elected to undergo surgery followed by chemotherapy and radiation and has now survived 5 years.
- Ralph feels that a cancer survivor needs three things: family support, good medical care, and faith that provides the strength to face each day with confidence. He says he is stronger today because of his cancer experience.

## **MR. DICK TENNEY, DENVER, CO**

- Two years ago, Dick underwent surgery for a gastrointestinal stromal tumor. Through an oncologist he met when his wife was being treated for breast cancer, he was able to enter a new clinical trial testing the drug Gleevec; to qualify, a patient had to have a large tumor and enter the trial within 8 weeks of surgery. After taking the drug for 1 year, Dick is receiving a CAT scan every 3 months and has remained cancer-free.
- If Dick's cancer recurs, he may need to take Gleevec again. He does not understand why he should have to pay \$2,000 a month to take this drug, considering the fact that he took the risk of entering the trial to help the pharmaceutical company study the drug's efficacy.
- Dick wants to help other cancer patients and has helped start a wellness organization in Denver. However, he is hindered by his uncertain status. He does not know whether he is a cancer patient or a person whose cancer has been cured. Also, since his particular form of cancer is rare, he does not know whether he can be of much help to others.

## **MR. RUSS BOYD, DENVER, CO**

- Russ' daughter, Nicole, was diagnosed with a neuroblastoma 3 years ago at the age of 4 and has had her left lung removed. Russ thanked the Make-A-Wish Foundation and Give Kids The World, two organizations that help families of children with cancer. These groups sent Nicole and several family members to Disney World for 5 days.
- Russ asked that the Panel consider the needs of caregivers, who themselves need support to continue to help pediatric cancer patients and survivors.

## **MR. MARIO MARCHELLO, CENTENNIAL, CO**

- Mario is cofounder of Legacy of Hope: The Stephen T. Marchello Scholarship Foundation. Stephen, Mario's son, was diagnosed with Ewing's sarcoma at the age of 16. During his treatment, Stephen accomplished his goals of graduating from high school and playing hockey in his senior year. He went on to graduate from college, was certified as an emergency medical technician, and was accepted into medical school before his cancer returned. Stephen was 28 when he lost his battle with cancer in 1999.
- Because education was so important to him, Stephen asked his parents to start a foundation to provide scholarships for cancer survivors. Many families of pediatric cancer patients use all of their college savings to pay for transportation, living expenses, and services that insurance does not cover, such as

reconstructive surgery. In 4 years, the Foundation has distributed \$65,000 in scholarships and grants to 16 high-school graduates. Information on the scholarship program is available on the Internet at [www.stmfoundation.org](http://www.stmfoundation.org).

### **MS. MARTHA HAILEY, DENVER, CO**

- Martha is a 17-year cancer survivor. In 1986, she was diagnosed with cervical cancer. The idea of not being able to care for her 7-year-old daughter was frightening, but Martha decided not to let fear take control of her life. In spite of fear of recurrence, she is proud of having survived chemotherapy, radiation, surgery, and other medical procedures. Her daughter, now 24, is serving in Iraq, and Martha is sure she will survive that, too.
- Many members of Martha's family have had cancer. Because of this apparent hereditary pattern, she worries about her daughter and feels that there should be a program to monitor young people in cancer-affected families and inform them about their cancer risks.

### **MS. SANDY HORROCKS, DENVER, CO**

- Sandy's husband, Jack Naylor, was diagnosed with prostate cancer in 1994. He went into remission and was cancer-free for over a year before his death last June.
- Sandy's background, including a master's in library science, enabled her to become an expert in doing cancer-related research, especially in locating clinical trials. She found that the NCI clinical trials Web site was not up to date because it relies on those conducting trials to provide updates. Sandy has developed a proposal to address this problem.
- Sandy proposes creation of a new group within the NCI to act as a liaison between doctors, patients, and researchers in order to give more cancer patients the opportunity to participate in appropriate clinical trials. This group would collect from all research-conducting institutions—including universities and pharmaceutical companies—the information needed to create a comprehensive and up-to-date database. Patients would register on the Web site by completing a brief application so that they can be matched with available trials. The new group would also provide consultation on procedures for participation under special circumstances, including assistance in obtaining compassionate waivers from pharmaceutical companies.

### **DR. von ESCHENBACH, NCI**

- Unlike pediatric trials, which enroll almost all eligible patients, adult cancer trials enroll only about 3 percent of all adult cancer patients. There is no single factor that contributes to this problem, and no single solution.
- The NCI has launched an effort to reengineer its clinical trials process and infrastructure, and the NIH is addressing the clinical trials infrastructure for all diseases. In addition, the National Dialogue on Cancer (NDC) has launched a clinical trials initiative as part of its effort to identify societal changes needed to bring safer and more effective treatments to cancer patients.
- Because partnership and collaboration are required to solve this problem, the NCI has formed a joint task force with the Food and Drug Administration (FDA). These agencies will share staff and resources to integrate scientific discovery and testing of new interventions through a process that includes collaborative interfaces with the pharmaceutical and biotechnology industries.

## **MS. KAREN HORNBOSTEL, DENVER, CO**

- Karen, a competitive cyclist like Lance Armstrong, was diagnosed with breast cancer in 1993 at the age of 39. She was treated with chemotherapy, but almost 5 years later was diagnosed with metastatic disease. She received a stem cell transplant but was again diagnosed in 1999. She has been in ongoing treatment since that time.
- Karen believes that cancer patients have the best chance for survival when they keep themselves as healthy and strong as possible. The long-term effects of cancer and its treatment should not keep people from living full, vibrant, high-quality lives.

## **MS. VICKI OTTOSON, DENVER, CO**

- Vicki spoke on behalf of her nephew, a 20-year-old college student who was diagnosed with Ewing's sarcoma a year ago. He was treated initially with radiation, which reduced his tumor by 50 percent, and then with chemotherapy and more radiation. He recently returned to college after proving cancer-free on his first CAT scan.
- Her nephew received excellent care at the specialized facility that provided his initial treatment, but he met with delays, indifference, and failure to agree on the best protocol when he returned to the regular adult health care system. There should be a continuous stream of coverage and planning centered around a single approach to each patient's care.

## **MS. BARB BRAZES, DENVER, CO**

- Barb was diagnosed 8 years ago with acute myeloid leukemia (AML). She received excellent care at the Rocky Mountain Cancer Center and never had to fight the system to receive the care she needed.
- In terms of "fighting" cancer itself, Barb felt uncomfortable with thinking of the experience in terms of conflict with cells that were part of her body. She received a bone marrow transplant from her sister, and she envisioned this procedure as using new cells from her "tough but fair" sibling to escort the cancer cells away from her body.

## **MR. VERN BELL, DENVER, CO**

- Vern spoke on behalf of his son Dakota, who was diagnosed with an inoperable brain tumor called a glioblastoma multiform, stage 4, a year and a half ago when he was 6 years old. He has been treated with both chemotherapy and radiation and is currently undergoing further chemotherapy.
- In addition to those treatments, Dakota is receiving nutritional therapy using a wide variety of supplements. Vern is interested in learning whether there are any organizations that can help families cover the high costs of dietary supplements.

## **MR. NEIL FISCHER, DENVER, CO**

- Neil spoke on behalf of his daughter Rachael, a 16-year-old cancer survivor. Soon after she was born, Rachael was diagnosed with a retinoblastoma. When an infant has cancer, the experience is very hard on the parents. Neil's family was fortunate to be able to stay in the Ronald McDonald House for 4 days. He urged the Panel to do as much as possible to support these kinds of resources for small children with cancer.

- Individuals also serve as heroes for children with cancer. Rachael read Lance Armstrong's book and was excited to receive an autographed poster.
- Neil reiterated the need for more information about nutritional concerns of cancer patients, especially concerning foods that are helpful in rebuilding damaged immune systems.

### **MS. RHEA THOMAS, DENVER, CO**

- Rhea was diagnosed earlier this year with malignant lymphoma. She is still undergoing chemotherapy and has found the support of her husband and five children to be a blessing.
- After her diagnosis, her son gave her Lance Armstrong's book, and this has been very inspirational to her.

### **MS. LINDSEY ETHRIDGE BUPENSMITH, DENVER, CO**

- Lindsey was diagnosed with Burkitt's lymphoma on Mother's Day at the age of 14. (She gave her mother a nice present that day and began chemotherapy the next morning.) Her parents spent every night in the hospital with her for the next 6 months.
- Although members of her family have not talked much about this experience, Lindsey said that their support was the reason she was able to survive her cancer experience.
- Lindsey teaches hearing- and language-impaired students; she uses Lance Armstrong as an example in the classroom to show that people with special problems also have special abilities.

### **MS. LORI WINGERTER, DENVER, CO**

- Two year ago, at the age of 38, Lori was diagnosed with colon cancer. She was treated with surgery, which was relatively easy to endure, and chemotherapy, which was very harsh. Lori feels that a more humane way to treat cancer must be found.
- Lori continues to see her oncologist and other medical doctors as well as practitioners of natural healing. She would like to see these two groups of care providers work together and give each other credence and respect. Lori has had to take responsibility for coordinating her care, but she has not been able to find information on combining traditional and alternative treatments.
- Cancer survivors need more and better information on how to stay healthy after treatment—not just through medical follow-up, but also through diet, exercise, and other factors that affect mental and physical well-being.

### **MR. JIM WILLIAMS, DENVER, CO**

- Twenty-five years ago, at the age of 20, Jim was diagnosed with mediastinal seminoma, a form of testicular cancer that appears in the chest. Surgery failed to remove the tumor, but radiation succeeded in eradicating it.
- Annual checkups have been performed to monitor late effects of the radiation treatment. Last April, a mole in the area that was irradiated was diagnosed as melanoma. Jim was referred to a surgeon, who examined his inverted left nipple and suspected breast cancer, which was confirmed by an oncologist.

- Jim's health is fine today, but he has experienced problems with insurance because he is self-employed.
- Jim is very concerned that most men—even those at high risk for cancer—are not regularly screened. There is no advocacy organization for men similar to groups like the Susan G. Komen Foundation.

### **MR. MILOS LINHARD, DENVER, CO**

- Milos, a cycling coach, was diagnosed with lymphoma in 1998. He has finished his radiation and chemotherapy, which he compares to a stage race in cycling. A patient may be up one day and down the next, but he wins the race if he completes all of the stages.

### **MS. SUE REICHARD, DENVER, CO**

- Sue, a very athletic person involved in running, biking, hiking, and skiing, suddenly had difficulty running 3 years ago and experienced gynecological problems. Her doctor at first shrugged her problems off as muscle spasms but reluctantly referred her to a gynecologist. This doctor first attributed her symptoms to age-related hormonal changes but reconsidered and ordered an ultrasound. Sue was finally diagnosed with stage 1 ovarian cancer. Detection of ovarian cancer at such an early stage is rare because it usually produces no early symptoms.
- After chemotherapy, Sue was able to resume her athletic activities, although at a reduced level. Last year, however, she began to experience extreme fatigue and a variety of other problems, including dizziness and tremors. The medication she was given caused high blood pressure and migraine headaches. Sue's muscle tissue has wasted away and she has constant pain in her legs.
- Sue believes that her recent medical problems are late effects of chemotherapy, but she has not been able to get any of her doctors to discuss this issue. This experience, and the fact that her first doctor ignored her problems, has led Sue to think of doctors as adversaries. She has turned to natural medicine and chiropractors for symptom relief.
- Sue related a story about her cousin who was diagnosed earlier this year with esophageal cancer. After his first visit for chemotherapy, he went home and committed suicide. Sue asked the hospital to let her know what was said to her cousin during that first visit, but the hospital never returned her calls.

### **MS. DEVARDA JONES, CAPITOL HEIGHTS, MD**

- Devarda, the mother of a cancer survivor, once devoted all of her waking hours to her role as a caregiver and felt guilty when she had to attend to her own needs. Her message to other caregivers is: "You are only as good at taking care of someone else as you are at taking care of yourself."
- Devarda eventually sought therapy, which enabled her to give herself permission to ask for help and to be interdependent rather than independent. Therapy provided her with an oasis where she could share her fears and doubts with someone who could give her objective feedback.

### **MR. RON KNAUBER, DENVER, CO**

- Ron was diagnosed 6 years ago with metastatic prostate cancer. He was treated with radical surgery, radiation, and hormone therapy. Ron described hormone therapy as a "chemical castration" that has drastic effects on the body.

- Ron reiterated the need for organized advocacy on behalf of men with cancer. He stressed the importance of screening. If he had had a PSA test 2 years before his symptoms appeared, his cancer probably would not have metastasized.
- Information is widely available through the Internet, Ron noted, but much of the material he has found is of questionable value. The current problem is not lack of information, but lack of accurate information.

### **MR. PATRICK O'LEARY, DENVER, CO**

- Patrick raised the issue of how well families communicate about cancer. His 87-year-old father is battling colon cancer; his wife's mother has been diagnosed with several different cancers since 1965; and his 25-year-old son was diagnosed 5 years ago with the same type of testicular cancer Lance Armstrong had—and he was equally successful in surviving it.
- Patrick is unsure whether he should ask his son the next time he sees him, “How is it going with the cancer fight?” He will be able to give his son an autographed copy of Lance's book, but he knows his son is not likely to read it because the subject is still painful for him to address. Patrick would like the Panel and others with expertise in this area to help families affected by cancer establish ongoing communication about their problems and feelings.

### **MR. WELLINGTON WEBB, DENVER, CO**

- Mr. Webb noted that men are acculturated differently than women in our society. They are taught to be tough and strong, which unfortunately means they are less likely to comply with guidelines for health screening. Men also need to be more open about discussing cancer among themselves. Prostate cancer is an especially difficult subject for men to address because of its sexual implications.

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

Dr. Leffall asked members of the Panel for their final remarks.

Dr. Kripke thanked those who spoke during both parts of the meeting. Hearing first-hand stories has a different impact than reading statistics. Many cancer survivors and family members spoke of the price of successful treatment. There is no question that the quality of life for cancer survivors is affected by their treatment. Surviving the disease is not the end of the cancer experience, but the beginning of the next phase of living with cancer. In addition to problems, however, cancer provides opportunities for learning, appreciating family support, and taking satisfaction in survival itself. Some people actually thrive as cancer survivors through the relationships they develop and the sense of accomplishment they achieve. Dr. Kripke reminded everyone about the availability of information through the Cancer Information Service. In terms of complementary medicine, she acknowledged that Asian cultures have done a much better job of combining complementary therapies and Western medicinal practice.

Mr. Armstrong said that his doctors told him after his treatment about what they called “the obligation of the cure.” He pointed out that a cancer survivor does not have to be an athlete or a celebrity to serve as a role model or a mentor. Although he respects the feelings of those who find cancer painful to talk about, he stressed the fact that everyone who tells a story, in a group or person-to-person, is fulfilling the obligation of the cure. Fulfilling this obligation starts at home, in the clinic, and in the community.

Dr. Rowland assured those who spoke during the meeting that their stories will make a difference. The NCI Office of Cancer Survivorship was created to respond to the expressed needs and interests of the growing number of individuals affected by cancer.

Dr. von Eschenbach noted that the audience was filled with very nice, polite people, but he wanted to remind them that sometimes it is all right to be aggressive and insist that a situation is not acceptable or that a problem must be addressed. He quoted a character from the television drama *The West Wing* who said that small groups of dedicated people can change the world. Sometimes small groups of people, like those at this meeting, need to “take the establishment by the throat” and demand that unacceptable things be changed. The President’s Cancer Panel is committed to listening and to changing things. As a final point of disclosure, Dr. von Eschenbach stated that he is a three-time cancer survivor and, therefore, is on the same journey as other cancer survivors.

Dr. Leffall concluded by noting that quality of life is an essential aspect of cancer survivorship—it is important not only that you live, but also how you live. The speakers at this meeting have engendered hope, which leads to one of the greatest human joys—the joy of anticipation.

### **CERTIFICATION OF MEETING SUMMARY**

I certify that this summary of the President’s Cancer Panel meeting, *Living Beyond Cancer: Survivorship Issues and Challenges Among Pediatric Cancer Survivors*, held September 5, 2003, is accurate and complete.

Certified by: \_\_\_\_\_

Date: 1/20/04

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