

MEETING SUMMARY PRESIDENT'S CANCEL PANEL

ASSESSING PROGRESS, ADVANCING CHANGE: CHALLENGES IN CANCER SURVIVORSHIP

August 26, 2005
Washington, DC

OVERVIEW

In 2003–2004, the President's Cancer Panel (PCP, the Panel) conducted a series of meetings focusing on cancer survivorship issues throughout the lifespan. As a result, the Panel learned that adolescent and young adult (AYA) cancer survivors represent an understudied population with specific unmet needs. The August 26 meeting brought together key stakeholders and decision makers, with the goal of identifying actionable steps that can be taken to implement select recommendations made by the Panel in its report, *Living Beyond Cancer: Finding a New Balance*. The information generated at the meeting will be used to accelerate implementation of the Panel's recommendations relative to AYA cancer survivors.

President's Cancer Panel

LaSalle D. Leffall, Jr., M.D., F.A.C.S., Chair

Margaret Kripke, Ph.D.

Lance Armstrong

National Cancer Institute (NCI)

Abby Sandler, Ph.D., Acting Chief, Institute Review Office, NCI; Executive Secretary, PCP

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

Dr. Leffall welcomed invited participants and the public to the meeting. He introduced Panel members, provided a brief overview of the history and purpose of the Panel, and described the aims of the current series of meetings.

The specific purpose of the meeting was to identify actionable steps that can be taken to implement recommendations made by the Panel in its 2003–2004 annual report entitled *Living Beyond Cancer: Finding a New Balance*. Dr. Leffall explained that the meeting would employ a format utilizing two roundtables, with the first centering on issues faced by AYA cancer survivors and the second on providing adequate access to care, including clinical trials, and insurance coverage for cancer survivors.

Invited participants were asked to prepare and submit a short summary describing their current position and their organizations' efforts relative to the recommendations being addressed. This information was shared among the roundtable participants prior to the meeting.

Participants were asked to address three questions relative to each recommendation.

- *What has happened with regard to this recommendation since its issuance in June 2004?*
- *What needs to be done to implement the recommendation?*
- *What should the priorities be in this area over the next two years?*

Discussants also addressed next steps, concentrating on specific courses of action to move identified priorities forward.

ROUNDTABLE I—ADOLESCENT AND YOUNG ADULT RESEARCH ISSUES

The first roundtable focused on three separate recommendations relative to AYA survivorship research issues; key points and next steps are summarized separately for each of the three recommendations.

Speakers

Alan Balch, Ph.D., Executive Director, Friends of Cancer Research

Archie Bleyer, M.D., Medical Advisor, St. Charles Medical Center; Director of AFLAC Research Projects in Adolescent and Young Adult Oncology, Children's Oncology Group

Brenda K. Edwards, Ph.D., Associate Director, Surveillance Research Program, Division of Cancer Control and Population Sciences, NCI

Ronit Elk, Ph.D., Scientific Program Director, Cancer Control and Prevention, American Cancer Society

Brandon Hayes-Lattin, M.D., Assistant Professor of Medicine, Oregon Health and Science University

Sandra J. Horning, M.D., President, American Society of Clinical Oncology; Professor of Medicine, Stanford University School of Medicine

Eugenie Kleinerman, M.D., Head, Division of Pediatrics, The University of Texas M.D. Anderson Cancer Center

Anna T. Meadows, M.D., Professor of Pediatrics and Medicine, University of Pennsylvania

Kevin Oeffinger, M.D., Director, Living Beyond Cancer: A Program for Adult Survivors of Pediatric Cancer, Memorial Sloan-Kettering Cancer Center

Kutluk Oktay, M.D., Associate Professor, Center for Reproductive Medicine and Infertility Department of Obstetrics and Gynecology, Weill Medical College of Cornell University

Julia Rowland, Ph.D., Director, Office of Cancer Survivorship, NCI

Scott B. Saxman, M.D., Senior Investigator, Clinical Investigations Branch, Cancer Therapy Evaluation Program, NCI

Doug Ulman, Chair, Director's Consumer Liaison Group, NCI

RECOMMENDATION ONE

A working group comprised of representatives from public agencies and private organizations with established surveillance databases should be convened to determine what additional data collection, infrastructure, and related funding would be required to better capture treatment and survival data on adolescent and young adult cancer survivors.

Key Points

- The National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program is providing better data on adolescent and young adult (AYA) cancer survivors. The U.S. Census Bureau provides the SEER program year-by-year data so that 18 year olds can be analyzed separately from 20 or 24 year olds. Databases from other localities, particularly Europe and Australia, have become available. Public-private combinations of organizations in the United States and Canada are also more visible, particularly the Young Adult Alliance Program.
- Many people treated for cancer as children do not know what kind of cancer they had, much less the treatment they received. The Texas Children's Cancer Center has developed the Passport for Care program, which will be implemented in partnership with the Children's Oncology Group (COG). The program is a Web-based resource for survivors and caregivers

that enables them to access individualized guidelines and resources with the eventual goal of portability, such that resources will be generated according to the patient's home ZIP code—even when the patient moves. This should be particularly appealing to young cancer survivors, who will be able to access their medical histories using the Internet and make those histories available, using secure access, to others who need to review them.

- Additional data on AYA cancer survivors are needed, including: the diagnosis, stage of cancer at diagnosis, treatment provided, and known common late effects of the treatment. Building a basic infrastructure for these data is an achievable short-term goal.
- Only a small percentage of young adult and adolescent cancer survivors make follow-up visits. Thus, currently available information about survivors in this age group is likely biased.
- The group discussed reasons young adult and adolescent cancer survivors do not return for follow-up care. Many young adults have negative feelings about doctors and hospitals, as well as a tendency to move around the country as they enter college and the workforce. Oncologists do not impart to their patients the importance of long-term follow-up care.
- The group discussed approaches to increasing the percentage of AYA cancer survivors who make follow-up visits. One approach would involve creating survivorship centers, aimed directly at this population, that interact and collaborate so that AYA survivors can make follow-up visits wherever they choose. Such centers should be designed following the community-based participatory research model by asking AYA survivors for their input.
- The Lance Armstrong Foundation (LAF) and the Nevada Cancer Institute are partnering to open a center for AYA cancer survivors in September 2005. It is branded LIVESTRONG and decorated with bright colors to appeal to survivors.
- The Children's Hospital of Philadelphia has a policy whereby all patients who complete cancer therapy have a discharge session to help them better understand their long-term follow-up care needs.
- The age range used to define adolescents and young adults needs clarification, as this is linked to research funding. Both the LIVESTRONG Young Adult Alliance and the Children's Oncology Group define the age range as 15 to 39 years (which includes adolescents) or 18 to 39 years (young adults only). When better information becomes available about the biology and pathogenesis of tumors in this population, cancers could be categorized as "AYA cancers," not by patient age.
- NCI recently held a conference on the eHealth initiative during which ways to capture information were discussed.

NEXT STEPS—RECOMMENDATION ONE

Key Points

- NCI is working with the LAF to form a progress review group (PRG) that will focus on AYA cancers. NCI will review the PRG's report and develop an action plan; follow-up will occur to determine whether milestones have been met.
- It was generally agreed that a "working group," as recommended by the Panel, could be established and must be a collaborative effort. The model of a national cooperative group with private funding and governmental support has succeeded; to do the same for cancer survivors 15 to 39 years of age would require leadership and collaboration within the cancer care community. NCI and ACS have taken the lead in forming similar collaborative initiatives in childhood cancer.
- In order to achieve progress, research questions to investigate in the area of AYA cancers and cancer survivorship need to be established.

- A continuing source of funding is needed to establish a database that will ensure that everyone who has cancer is registered along with his or her treatment records; this database must meet all privacy requirements of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and other regulations. NCI is one funding source, but the key is getting people to commit to take on whatever is within their professional and organizational purviews.

ORGANIZATIONAL COMMITMENTS—RECOMMENDATION ONE

- Dr. Rowland and Mr. Ulman will investigate whether the existing PRG (formed by NCI and LAF) could serve as the working group recommended by the Panel.

RECOMMENDATION TWO

The National Cancer Institute and other cancer research-sponsoring agencies should raise the priority of and increase funding for research on the issues of cancer survivors diagnosed as adolescent or young adults. Studies of biologic differences in cancer types and host factors and of late effects of cancer and cancer treatment in this population should be emphasized to improve the knowledge base and inform the treatment, prevention, and quality-of-life interventions that are designed to benefit this population.

Key Points

- The number of research grants awarded related to cancer survivorship has increased dramatically over the past 10 years; this includes research on adolescents and young adults. Ten years ago, the NCI Office of Cancer Survivorship (OCS) had 16 grants; it now has more than 120. The OCS performs an annual portfolio analysis across the National Institutes of Health to see what studies are following individuals more than 2 months post treatment. The fiscal year 2004 portfolio analysis (for studies that were funded from October 2003 to September 2004) identified 212 studies (about 12 percent) in the AYA arena.
- The Childhood Cancer Survivor Study (CCSS) can be used as a model for AYA cancer survivor research. The CCSS database includes 14,000 survivors, and the cohort is going to be extended. It was noted that the database is not a representative sample, which is a requirement of population studies.
- Cancer in adolescents and young adults is different from cancer in younger and older age groups, and treatment design must reflect these differences. SEER data show that 5-year survival rates in the United States for all stages of all cancers in people under 30 combined is 10 to 20 percent lower than for those over age 50. A recent article in the *Journal of Clinical Oncology* reported that microsatellite instability in young adults does not respond to adjuvant chemotherapy the way it does in older cancer patients. Data from the Nurse's Health Study indicated that younger female breast cancer survivors have persistently worse functional outcomes than do those in older cohorts.
- The SEER database will have data on second cancers within the prevalent population, which will make it possible to study patterns over time. Given the low prevalence of AYA cancer survivors, there is not a large amount of data on this population, but SEER remains a rich data source.
- The group discussed a number of challenges to implementing the Panel's recommendation.
 - Cancer research funding should be in proportion to the population that carries the largest burden of the disease. NCI currently funds a larger proportion of research in adolescents and young adults than this age group represents in the larger cancer population. Thus, it is difficult to request increased NCI funding.

- More funding sources are needed. Researchers should not rely solely on NCI funding; the group must consider creative funding mechanisms and approaches using extant resources to leverage opportunities. For example, funding may be available in unsolicited R01 or U-type grants; the study of biologic differences in cancer lends itself to the R01 funding pool.
- However, the NCI has some survivorship investigators on standing study sections, including individuals with expertise in behavioral science and epidemiology. Survivorship research needs greater representation in study sections. It is a challenge to find appropriate study sections to review survivorship research topics.
- Tissue specimens for AYA cancer patients are underrepresented compared with cancer patients in the younger and older age groups. There are fewer banked specimens for patients 18 to 36 years of age than for those up to 15 years of age, despite the fact that the incidence of cancer between ages 15 and 40 is seven times higher. There is a lack of clinical trials, a lack of tumor procurement, and failure to use the tumors available in banks.
- It was suggested that researchers analyze available data from the past 20 years to study the effect of age on outcomes and biologic findings.
- Databases and registries have been established; however, because many effects occur long after treatment, data regarding the full impact of treatment will not be available for years.
- Finding patients and collecting treatment information is difficult because many young adults receive treatment outside of NCI-designated Cancer Centers; up to 85 to 90 percent of young people are treated in community facilities, more than for any other age group.

NEXT STEPS—RECOMMENDATION TWO

Key Points

- It is vital to raise awareness of the Panel’s recommendation on survivorship research.
 - The American Society of Clinical Oncology (ASCO, the Society) could help by promoting educational efforts at its meetings and through its publications for ASCO investigator-supported awards.
 - M.D. Anderson held a conference designed to raise awareness; it is bringing investigators together for collaborative efforts to address the points in the Panel’s recommendation.
- The group discussed ways to take advantage of current information assets through retrospective reviews of existing data: studying age as a function of biological outcomes, biological mechanisms, and survival issues. Existing data applying the specific research questions raised in the Panel’s recommendation could be reviewed. It was suggested that the cooperative group tissue banks be studied. Dr. Rowland reported that NCI is reviewing the larger NCI-funded epidemiology cohorts, recognizing that many have generations of individuals who have gone through treatment and later developed identified tumors.
- The group discussed creative approaches to funding the research described in the Panel’s recommendation.
 - Organizations funding studies in underserved populations should be investigated as a possible source of support; adolescents and young adults could be considered an underserved population. It was reported that studies on follow-up care are competing successfully for rare-disease dollars. Approximately 10 percent of the American Cancer Society’s (ACS) research budget goes to the poor and medically underserved.

- The ACS spends \$100 million on research annually; researchers are not sufficiently aware of the ACS funding mechanism.
 - The insurance industry has a role to play in funding this research. AFLAC funds two Young Investigator Awards in young adult oncology through the CureSearch and Oncology Group mechanism. Insurance providers need data in order to make informed decisions about what treatments to cover.
 - Existing awards (e.g., Young Investigator, Career Development) could be directed toward the specific research questions in the Panel’s recommendation. It was suggested that a group of organizations, each with some ability to fund investigators, could agree to target awards toward these areas of interest.
- Adolescent and young adult survivor issues could be included in criteria for Cancer Center Support Group (CCSG) grants. Comprehensive Cancer Centers should be asked to demonstrate what they have done for adolescents and young adults as a part of the CCSG grant renewal process.
 - Journals could encourage study of AYA survivor issues and challenge authors to include this age group in their studies.
 - A study section on molecular integrative clinical aspects of survivorship issues should be established. There is a need for a study section with expertise to review proposals regarding the molecular mechanisms of the damage that cancer drugs do to eggs and sperm cells. This could lead to development of noninvasive methods to prevent this kind of damage.
 - The group discussed collaborative approaches to research—i.e., accruing participants from multiple centers. A clinical trial was described of young adults (under age 30) with acute lymphoblastic leukemia involving the Cancer and Leukemia Group B, the Southwest Oncology Group, and COG. The trial will investigate why outcomes for young adults are so much poorer than those for teenagers and younger children. This approach would be a model for other cancers in young adults and could accrue not only patients, but also tumor specimens that would be useful in molecular biology studies.

ORGANIZATIONAL COMMITMENTS—RECOMMENDATION TWO

- Dr. Rowland will encourage improved representation by survivorship investigators in study sections.
- NCI will investigate approaches for combining and leveraging resources to improve basic science in the AYA arena as well as in survivorship in general. Scientists in the extramural community need to study the biology of survivorship and its impact on risk prevention.

RECOMMENDATION THREE

Further research should be conducted to determine what fertility preservation options are possible for childhood and young adolescent cancer patients.

Key Points

- Awareness about fertility preservation issues is growing, although levels of awareness vary geographically across the United States. Initiatives are underway to help increase awareness among oncologists, reproductive endocrinologists, patients, and the media. The American Society of Reproductive Medicine has established a fertility preservation special interest group to educate colleagues and the public about the importance of fertility preservation issues and to foster collaboration.
- ASCO is developing fertility preservation guidelines for oncologists. ASCO’s Fertility Preservation Committee is developing the guidelines to provide patients with appropriate

recommendations based on the chemotherapy they receive. The guidelines will be published in ASCO's journal within the next 6 months.

- The oncology community is becoming more sensitive to the need for early doctor-patient dialogue about fertility preservation issues. In the past, oncologists focused almost exclusively on helping patients survive their disease with little attention given to long-term consequences of treatment. Now that cancer patients are living long-term, post-treatment consequences must be discussed. Cancer patients need to talk about what is important in their lives, what they hope to do in the future, and how those plans might be altered by their treatment.
- Participants described current research projects related to fertility preservation.
 - Several studies are measuring the effectiveness of efforts to communicate and educate about sperm banking. One study is designed to assess caregiver knowledge about sperm banking and the effectiveness of efforts to inform adolescents on the topic. In addition, a questionnaire is being developed to measure what oncologists know about sperm banking options. Another study is investigating why some adolescent patients opted for sperm banking while others did not. Patients and parents are asked how they learned about sperm banking, how they felt about the process, and their plans for the future.
 - Dr. Meadows described a proposal for a highly experimental project that would attempt to mature, *in vitro*, sperm that had been collected in biopsies of prepubertal boys. The process holds great promise for the future but is not yet in progress.
 - The Center for Reproductive Medicine and Fertility at Cornell and Memorial Sloan-Kettering Cancer Center will be launching a joint program designed to streamline patient care and educate oncologists and fertility doctors about cost issues. Cancer patients who contact the program receive immediate fertility counseling; some patients who arrive in the morning are able to start an IVF cycle (to start freezing their eggs and embryos) that afternoon. It was suggested that every trainee in the cancer field who is going to deal with young people should rotate through this program.
 - Dr. Oktay and his colleagues are conducting a pilot study to evaluate the utility of biological markers to measure the true amount of reproductive damage resulting from chemotherapy.

NEXT STEPS—RECOMMENDATION THREE

Key Points

- Men and women experience fertility loss differently; thus, they need gender-specific solutions to address their needs. For example, women tolerate more chemotherapy without impacting fertility but may have early ovarian failure. Men generally preserve fertility better than women. Cryopreservation of sperm is effective, but the issue is more complicated for women: Eggs do not freeze as well as sperm; performing IVF and freezing embryos requires time; and some stimulation protocols increase estrogen levels, which could fuel hormone-sensitive cancers such as those of the breast and endometrium.
- The group discussed fertility preservation research needs.
 - Further research is needed to improve understanding of how current treatments affect fertility. Many practicing physicians are not aware of the likelihood that a patient at a given age would be rendered infertile (or a woman would have premature menopause) as an outcome of a treatment regimen. A current Hodgkin's trial (accruing 800 patients) includes an analysis of baseline fertility and follow-up.

- Clinical trials can answer important questions, such as how many doses of chemotherapy result in male or female infertility or premature menopause. In order to provide useful data, the trial protocol and therapy need to be consistent.
- In a recently published study, 11 young men who had had four cycles of COP (cyclophosphamide, vincristine [Oncovin], and prednisone)-ABV (doxorubicin [Adriamycin], bleomycin, and vinblastine) were all rendered infertile. The treatment was intended to preserve the participants' fertility, but it failed to do so. Women need quantitative information about what each drug does to their ovaries so that they can factor such information into their treatment decision; this may require midterm clinical studies coupled with basic studies that can quantify damage.
- Researchers should be encouraged to investigate drugs that have reduced gynecotoxic effects.
- Animal and xenograft models could be used to help fertility preservation research keep up with rapid changes in chemotherapy and other treatments. Often, by the time a 10-year study is completed, chemotherapy regimens have changed, making the research findings obsolete. If *in vitro* testing of human tissue was performed in conjunction with chemotherapy, new drugs could be tested immediately, avoiding a 10-year delay to see how the new drug affects fertility.
- The safety and efficiency of fertility preservation approaches should be studied. Alternative stimulation protocols should be investigated so that women with hormone-sensitive cancers (e.g., breast and endometrial) can freeze their eggs and embryos without risking cancer recurrence. The safety and efficiency of ovarian transplantation and cryopreserved ovarian tissue are still unknown.
- Research is needed to determine the best way to explain fertility issues and preservation options to younger patients. It is difficult to discuss this subject with a 15 year old who must assent, if not consent, to a procedure. A survey of current practices could be used to measure the effectiveness of educational efforts; this would be relatively inexpensive research.
- Studies are needed to measure the cancer survivor population for whom fertility will be compromised. Researchers should determine the incidence of males with testicular cancer who are infertile at diagnosis.
- Research is needed to determine the mechanism of chemical damage. Currently, it is not clear how damage occurs.
- Fertility preservation studies could be built into a fellowship program; endocrinologists should be involved in this type of effort.
- Referencing the background materials provided to meeting participants, it was noted that abundant data are available on Hodgkin's disease and non-Hodgkin's lymphoma, the primary diagnoses in the AYA age group. Unfortunately, these data are not well known, not accessible, and incomplete. A more concerted effort should be made to examine the data from an exposure as well as disease orientation.
- Fertility and reproductive history and outcomes should be included in existing research. An analysis of pretreatment fertility and reproductive history and outcome analysis could be incorporated into current clinical research. Requiring collection of reproductive history data also ensures that this important discussion takes place before the patient enrolls in a trial.
- The best approach, although not the most practical, is to follow cancer survivors for 10 to 15 years to see what happens to their fertility. However, it would be very difficult to fund

a long-term study examining the entire reproductive lifespan to compare fertility of cancer survivors with a control group.

- More sensitive fertility indicators are needed. Existing research relies on crude fertility indicators; thus, the amount of damage chemotherapy or combination chemotherapy causes is likely being underestimated. Early studies looked only at menstruation as evidence of fertility: If a woman had taken a specific drug and was still menstruating 3 years later, she was considered fertile. However, testing for biological markers such as follicle-stimulating hormone and estrogen show that many women who are menstruating are actually infertile. Most studies of male fertility rely upon sperm count as a fertility indicator; however, it cannot be assumed that a certain sperm count is commensurate with fertility.
- Faster research funding processes are needed to keep pace with the introduction of new cancer treatments. R01 funding is a slow process; by the time a grant related to fertility research is funded, new treatment drugs will have been introduced. It was suggested that a center, researcher, or group of investigators be identified to perform fertility research based on record of accomplishment.
- It was suggested that combined cancer and fertility centers be established to help cancer survivors address reproduction issues. Pairing fertility experts with oncologists is important.
- Psychosocial support systems are needed to help cancer survivors deal with infertility and adoption issues. Although drugs are changing and options are improving, many patients remain infertile. Infertility is an issue commonly raised by the young adult population.
- The Cancer Therapeutics Evaluation Program (CTEP) provides ancillary funds for translational research as part of the cooperative groups. Fertility and fertility preservation research should be incorporated in cooperative group trials and the NCI-sponsored trials.
- Dr. Rowland urged the President's Cancer Panel to endorse a recommendation from the Clinical Trials Working Group that NCI set aside dollars for correlative science enterprises.

ORGANIZATIONAL COMMITMENTS—RECOMMENDATION THREE

- ASCO will assist in identifying the information gaps and critical research needs in fertility preservation research; the Society has a history of putting together expert panels for this kind of effort. The ACS should also be involved in this effort. The following research questions should be given priority:
 - Investigate the true extent of cancer treatment damage to fertility.
 - Develop model systems to test new drugs without having to wait 10 to 15 years to determine their impact on fertility.
 - Examine the effectiveness and safety of fertility preservation options, including ovarian tissue freezing and egg freezing.
 - Examine the mechanism of damage so that nonsurgical approaches to fertility preservation can be developed.
 - Investigate other issues relating to reproduction, safety of pregnancy post hormone-sensitive breast cancer as well as the menopausal issues of young children and women who receive chemotherapy.
- ASCO will look into undertaking research to measure the effectiveness of the awareness campaign related to its upcoming fertility preservation guidelines. The program would examine oncologists' behavior before and after the guidelines are issued to determine whether marketing efforts increase awareness and utilization of the guidelines.
- Dr. Oktay volunteered to develop an educational program for the ASCO meeting to increase awareness of fertility preservation issues.

- Dr. Oktay agreed to contact the American Society for Reproductive Medicine to develop collaborations with other organizations to: (1) seek creative funding approaches; and (2) consider jointly funded fellowships.

PUBLIC COMMENT

Susan Weiner, Ph.D., President and Founder, Children's Cause for Cancer Advocacy

- The follow-up, educational, and psychosocial needs of the AYA population should be considered in developmental terms. A categorical approach to adolescents and young adults is neither realistic nor the most ecologically valid way to deal with this particular population. The psychosocial needs of 24 year olds are the same whether they were treated for cancer or cystic fibrosis and whether they were treated at age 19 or age 9.
- The larger questions about personalized medicine, how to create incentives, and how to approach drug discovery should be examined for adolescents and adults.
- Cooperative groups are developing protocols that meet the disease needs of a particular age group based on known evidence gathered over the past 30 years.

Robert Comis, M.D., President and Chairman, Coalition of Cancer Cooperative Groups (CCCG)

- Dr. Comis reported on statistics from the Eastern Cooperative Oncology Group (ECOG) database. In the last 10 years, ECOG accrued about 47,000 patients. About 9 percent (4,600) were 39 years of age or younger, roughly matching the proportion of the overall population that is in this age group. He estimated there would be about 22,000 patients across the system. About half of the patients are breast cancer patients, whereas lymphoma, leukemia, and melanoma patients compose the other half.
- CCCG could spearhead an effort to collect information from all the groups.

Martha Hare, Ph.D., R.N., National Institute of Nursing Research (NINR)

- NINR held a workshop in August 2003 that focused on putting forward a research agenda for children and adolescents with cancer. Some of the gaps mentioned today were discussed in this workshop. One purpose of the workshop was to determine what research NINR, NCI, and others might fund.
- NIH's Community Participatory Research Initiative could be leveraged to reach some of the adolescent populations and the issues discussed this morning.

Karen Albritton, M.D., Director, Adolescent and Young Adult Oncology, Dana-Farber Cancer Institute

- The Panel must clarify the distinction between research on AYA survivors of childhood cancers and research on AYAs diagnosed with cancer. These are two very different research agendas.
- The infrastructure for collecting childhood cancer data must be enhanced. COG registers a large percentage of patients who are diagnosed before age 15. The CCSS, although inadequate in follow-up, is the best database available and is doing a good job. Funds are needed to enhance the procedures and for people at COG institutions who perform follow-up, track patients, and tie the information into the Passport for Care system and to the survivorship clinic.

- The database for cancer patients who are diagnosed as adolescents and young adults is inadequate. SEER does not adequately capture the AYA population because cancer is considered a rare disease in this age group. AYA cancer patients are spread out among pediatric oncologists, medical oncologists, and the community medical oncologists at academic centers. No databases are capturing treatment and survivorship data for patients diagnosed as AYAs.
- AYA cancer research must become a part of a career pathway. Pediatric oncologists and medical oncologists are not encouraged to conduct AYA research. Using ASCO and Young Investigator awards to encourage this kind of research is a great approach.
- Collaboration between pediatric and medical oncologists must be encouraged; thus, the request for applications (RFA) process should require them to work in partnership.

Matthew Zachary, President, Chair, and Founder, Steps for Living

- The Panel should not overlook the fact that adolescents and young adults are generally more responsive to marketing strategies. Apple Corporation might be interested in becoming involved, as Steve Jobs is a cancer survivor. Venues such as MTV, Comedy Central, and high schools should be used to disseminate information.
- Mr. Armstrong pointed out that other issues have been made “hip” by MTV (e.g., AIDS, the Third World, voting) and expressed the hope that the sight of 50 million people wearing yellow wristbands would send the message that cancer is a hip issue worthy of continued attention.

Cherie Nichols, M.B.A., Director, NCI Office of Science Planning and Assessment

- The AYA progress review group (PRG) is moving at a fast pace: leadership has been established, a meeting is scheduled for September, and the roundtable (which will include about 100 participants from the community) will meet in early spring 2006. A report will be published by late spring, and activities will have begun by fall 2006.
- The AYA PRG is different from other NCI PRGs, which have typically focused on a disease site. This is a broad, scientific PRG being cosponsored by LAF, a non-Government organization. The community will not only make recommendations, but also be involved in making those recommendations happen. A successful PRG requires that the community embrace its recommendations.
- AYA PRG information is available at <http://planning.cancer.gov/>. Input from Panel members and other participants is welcomed.

Lou Greenzweig, Member, Board of Trustees, Steps for Living

- Public high schools require a health and physical education program that includes information about diseases. Including AYA cancer issues in these programs could reach every student in America at age 14.
- Mr. Greenzweig would like to see a national medical card containing a patient’s medical history data.

Katherine Walsh-Burke, Ph.D., M.S.W., President, Association of Oncology Social Work

- Every cancer research protocol should include identification of psychosocial risk factors and analysis of those data by experts. Current cancer research does not follow the same interdisciplinary model that practice does. Most comprehensive cancer programs include

psychosocial experts because psychosocial factors significantly influence who is diagnosed, how quickly they are diagnosed, and how effectively they are able to comply with the treatment. Findings from a study about psychosocial distress in wives of young adult cancer patients indicate that wives with young children at home who were not employed outside the home full-time had significantly higher stress levels. Although the researchers had collected insurance data, they had not included it in their analysis. A psychosocial expert would have recognized how their insurance status would have affected the wives in the study.

ROUNDTABLE I: FINAL COMMENTS AND RECOMMENDATIONS

- Identify well-funded donors who can offer significant financial support to research areas that are not well studied. For example, the Longaberger Foundation is supporting research on lymphedema.
- Surveillance must be improved. Effective ways must be developed to record data electronically so that surveillance can be maintained. The PRG and ASCO are fully committed to this.
- The Panel's focus on AYA cancer survivor issues has made adult oncologists more open to collaboration.
- The scientific community determines the research priorities to ensure that limited financial resources are used wisely.
- Despite the progress made during the past year, the United States is falling behind other countries in terms of cancer survival rates and clinical trial accrual. For example, Australia's 5-year survival rate in persons between 20 and 35 years of age is 10 percent ahead of that of the United States; that is, Australian cancer patients in this age group have a better chance of surviving cancer for 5 years than U.S. cancer patients in the same age group. According to NCI data, the number of U.S. patients 20 to 40 years of age who enter a clinical trial has decreased from about 5,000 in 1998–1999 to about 2,000 in the last CTEP database. The United Kingdom has increased its accrual of young adults into clinical trials.
- Nursing research is ahead with respect to conducting studies in the community versus in a clinic. The nursing oncology group is using cell phones to conduct research, and iPods may be next.
- A compendium for a monograph that relates to adolescents and young adults is under development. The project has been developed by NCI's Division of Cancer Control and Population Sciences with people in the community who are determined to disseminate the information.
- Fertility preservation research needs more funding, more creative funding mechanisms, faster funding mechanisms, and long-term funding that would allow research on the long-term and late effects of cancer.
- Cancer and fertility centers and their corresponding societies should be encouraged to collaborate in efforts to educate consumers and the oncology and fertility medical communities.
- Developing the COG guidelines for follow-up of childhood cancer survivors took a long time. ASCO is developing guidelines for follow-up of adult cancer patients. Now is the time to study the effectiveness of those guidelines and who is using them. For example, it is important to know whether the guidelines for cardiac long-term effects surveillance catches patients early enough to make a difference.

ROUNDTABLE II—INSURANCE AND ACCESS ISSUES

The second roundtable focused on insurance coverage and access to cancer care issues. Participants were asked to address four of the recommendations together as part of their roundtable discussion.

Speakers

Karen Albritton, M.D., Director, Adolescent and Young Adult Oncology, Dana-Farber Cancer Institute

Lindsay Nohr Beck, Founder and Executive Director, Fertile Hope

Robert Comis, M.D., President and Chairman, Coalition of Cancer Cooperative Groups

Gail McGrath, President and National Director of Government Affairs, National Patient Advocate Foundation*

Andy Miller, M.H.S.E., C.H.E.S., Associate Director of Public Health, Lance Armstrong Foundation

Eddie Reed, M.D., Director, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention

Doug Ulman, Chair, Director's Consumer Liaison Group, NCI

Katherine Walsh-Burke, Ph.D., M.S.W., President, Association of Oncology Social Work

Susan Weiner, Ph.D., Founder and President, Children's Cause for Cancer Advocacy

Brock Yetso, Executive Director, Ulman Cancer Fund for Young Adults

RECOMMENDATION ONE

Adequate reimbursement for prosthetics must be provided, and it must be recognized that:

- Many prostheses must be replaced periodically.
- Access to prostheses is an integral part of psychosocial care for cancer.

RECOMMENDATION TWO

Coverage should be provided routinely for psychosocial services for which there is evidence of benefit both during treatment and post-treatment as needed.

RECOMMENDATION THREE

Public and private insurers should provide reimbursement for risk assessments, surveillance, and other follow-up care for cancer survivors, including care provided by appropriately trained non-physician personnel.

RECOMMENDATION FOUR

Fertility preservation procedures and infertility treatment services should be covered by health insurance for cancer patients/survivors whose fertility will be or has been damaged by cancer treatment.

* Ms. McGrath participated on behalf of Nancy Davenport-Ennis, who was unable to attend.

Key Points

- Some advancements have been made toward accomplishing the Panel's recommendation on fertility preservation and infertility treatment.
- Fertility preservation awareness is a key issue; evidence-based solutions exist (e.g., sperm banking, embryo freezing). Awareness and education issues must be addressed first; insurance coverage will not solve a problem that patients do not know they have.
- Data are needed to assess the incremental costs of adding fertility preservation coverage. A Massachusetts study showed that including mandated infertility coverage on an insurance plan costs less than \$1 per year per person.
 - Fertile Hope has started an advocacy campaign on Capitol Hill in partnership with the Lance Armstrong Foundation to educate policy makers. A resolution supported by a number of Democratic and Republican representatives has been introduced.
 - A large, self-insured investment bank in New York City has added fertility preservation coverage to its health plan. Believing that the bank is the first business to take this step, its representatives met privately with Fertile Hope to discuss how to announce the new coverage in a way that would encourage other companies to follow its lead.
 - Thirteen states have mandated fertility coverage. However, the mandates define *infertility* as unsuccessfully trying to conceive for 1 year. Unfortunately, cancer patients who try to bank their sperm or freeze embryos in advance of treatment find that they do not meet this criterion.
 - Fertile Hope's financial assistance program has helped meet the fertility needs of hundreds of cancer patients. The program is a public-private partnership wherein pharmaceutical companies donate medications and physicians donate their services. This fertility preservation financial assistance program is one of the few that are sustainable.
- Successful insurance awareness and education activities are underway. These efforts attempt to help patients and survivors understand how insurance works.
- Expanding the types of services covered by insurance will require evidence of a cost benefit for the insurer. Physiological, medical, and economic outcomes must be documented to make a case for profitability. Data must demonstrate that services reduce health care costs, return people to the workforce, and enable them to continue to be productive, which in turn means they will be able to pay for insurance coverage.
 - Measuring the effectiveness of existing interventions is critically important. These evaluation activities will help develop the evidence base needed to demonstrate the value of these interventions.
 - Studies have shown that psychosocial services provided by a broad, diversely trained group of professionals improve quality of life. Unfortunately, few of these studies have tied this positive outcome to reduced economic costs, increased health care utilization, or reduction of psychosocial-related late morbidity associated with the illness.
 - Research on cost outcomes is not being conducted because systematic funding is not available. Research involving these interventions (particularly psychosocial) is expensive because the interventions themselves are costly. This puts the research above the funding threshold.
 - The Ulman Cancer Fund attempts to inform young people on college campuses that they may not have insurance coverage between graduation and starting their first job. The Ulman Cancer Fund is exploring marketing strategies to reach young adults and educate

them about the importance of having insurance, different levels of coverage, and insurance costs.

- The Children’s Cause for Cancer Advocacy collaborates with local groups that have access to adolescents and young adults to provide educational programs. State health insurance representatives provide state-specific information at Children’s Cause educational workshops.
- Insurance companies seem willing to support education and awareness for young adults, a population segment they are not currently reaching. Insurance companies are well known for educational mailings and public service announcements as a means to reach current and potential customers. These companies are interested in creating public-private partnerships where everyone would benefit—young adults as well as insurers.
- Some progress has been made in providing psychosocial care to adolescents and young adults (AYAs). The LAF Young Adult Alliance has succeeded in working with organizations that are better placed to provide psychosocial care to AYAs. For example, AYAs often turn to the Ulman Cancer Fund and Planet Cancer (<http://www.planetcancer.org>) for psychosocial services rather than attend support groups at cancer centers.
- The Association of Oncology Social Work (AOSW) offered a free online Cancer 101 course designed to inform social workers about cancer-related psychosocial issues. The program, offered in collaboration with the National Association of Social Workers, introduces social workers to available psychosocial resources and programs so that social workers in a variety of settings can at least make referrals. In the first 6 months since its initiation, 15,000 social workers have completed the course. It is an easily accessible method of education that could be expanded for dissemination to community practitioners, including physicians, nurses, and social workers.
- Congress has set aside close to \$1 million for an NIH study to investigate provision of psychosocial services to cancer patients and others with life-threatening illnesses. This funding has been federally mandated and will be moving forward.
- Collaborations have increased the success of legislative advocacy. A partnership between the AOSW and the Patient Advocacy Foundation was effective because its presentation included survivors who spoke from personal experience and experienced social workers who have helped survivors navigate the complex health care system. Collaborative efforts are likely to increase because of efforts such as the LAF Young Adult Alliance.
- The American Psychosocial Oncology Society offers online training programs designed to train individuals to deliver psychosocial care to the growing cancer survivor population.
- The Ulman Cancer Fund has a pilot program at Johns Hopkins for the young adult population; every young adult patient is connected with a young adult survivor to promote communication with the medical team and gather resources to make the patient’s cancer journey easier and improve quality of life.
- Interdisciplinary collaborations produce results. The success of collaborations among advocacy organizations, oncology service providers, and others is the result of bringing together experts from different fields. For example, social workers had input into the design of a Children’s Oncology Group study funded by NCI. LAF funds the community organization that provides the intervention.
- The benefit of psychosocial services in hospice care has been demonstrated. Dr. Walsh-Burke described a study sponsored by the National Hospice and Palliative Care Organization. Two social workers compared costs of providing hospice care when a social worker was involved with those incurred when a social worker was not involved. Their results showed that hospice

care cost less when a social worker was involved. Conducting the study was relatively simple because it involved a very circumscribed set of services.

NEXT STEPS

General

- Ensure that survivor services legislation includes provisions for AYA populations as well as appropriate funding. The cancer survivor community must ensure that proposed legislation would lead to programs with demonstrated value for AYAs. In addition, Federal funding for these programs must be provided.
- Specific revenue sources must be identified to continue support for existing programs. For example, case managers in Ohio's Breast and Cervical Cancer Early Detection Program (BCCEDP) interface with 200 or 300 clients and function as navigators to help individuals gain access to psychosocial and other types of support. If funding for this program remains flat, the number of people the program can serve will decrease as costs rise.
- Follow-up care should be available to cancer survivors being treated outside of a comprehensive care setting. Most comprehensive care programs include prosthetic devices, psychosocial services, and fertility preservation and provide the expertise to help people access them. Unfortunately, there is no mechanism to pay for those services outside of the comprehensive care setting.
- Follow-up studies are needed in order to identify late effects of treatment. Most people have some level of follow-up for second malignancies or recurrence but not for late effects of treatment. Many times, people are not aware of the late effects that exist. The proposed health passport should include guidelines for ongoing monitoring for secondary health effects. Data on late treatment effects will be needed as long as cancer treatment continues to evolve at a rapid pace. Follow-up research will provide a source of continuing information.
- Meeting the health literacy needs of AYAs means making the issue "hip." There are models to use. For example, the Vote or Die campaign increased voting in that age group in the United States.
- Important messages—such as the value of being engaged in one's own health care decisions—must be delivered at appropriate literacy levels. Even highly educated people have a difficult time understanding their medical coverage; for others, it is even more challenging. Communications must be designed to fit audiences at a variety of educational levels.
- Diverse patient navigation models should be funded and studied for efficacy. What works in one community may not work in another. Professional nurses and social workers are providing navigation services, helping clients deal with the most complex issues in the health care system. This is only one model; others are needed.

Recommendation One

Adequate reimbursement for prosthetics must be provided, and it must be recognized that:

- Many prostheses must be replaced periodically.
- Access to prostheses is an integral part of psychosocial care for cancer.

Key Points

- There is a need to identify best practices of insurers and convince other insurers to model them. For example, birth control pills and reconstructive surgery for breast cancer are now covered; this was not true in the past. Investigate how these coverage changes were made and

apply the same approach to expanding coverage to include periodic replacement of prosthetics.

- Measure the benefits to survivors and determine the incremental costs for providing prosthetics to childhood and young adult cancer survivors. Dr. Weiner suggested that insurance companies that provide prosthetic coverage could be approached for cost information.
- Inventory existing public- and private-sector resources. If such resources exist, patient navigation can help individuals connect with them. If they do not exist, they should be established.

Recommendation Two

Coverage should be provided routinely for psychosocial services for which there is evidence of benefit both during treatment and post-treatment as needed.

Key Points

- Evidence of the benefits of psychosocial risk assessments is needed in order to identify resources to provide the services and support the push for insurance coverage. Existing resources may include community organizations (e.g., LAF, The Wellness Community, *CancerCare*, and American Cancer Society Outreach). Many cancer patients will experience depression. A clinically depressed patient needs to be properly evaluated and offered an appropriate intervention; this should be covered by insurance.
- *CancerCare* should be involved in setting priorities for this recommendation. According to Mr. Miller, *CancerCare* has been providing psychosocial support longer than most organizations in this country and has accumulated a vast wealth of knowledge.
- According to Dr. Reed, Centers for Disease Control and Prevention (CDC) programs should be modified to encompass psychosocial services. Currently, these programs provide cancer screening services to un- and underinsured people. Through the BCCEDP, for example, when a malignancy is found, both un- and underinsured patients become eligible for Medicaid.
- More evidence of benefit is needed. The group discussed efficient ways to gather this evidence, such as identifying opportunities to collect psychosocial services information in existing studies. According to Dr. Walsh-Burke, some studies may not recognize that a survivor's participation in a community support group is a significant factor influencing his or her positive outcome. Steps should be taken to ensure that psychosocial risk factors and interventions are a part of the data collected and analyzed for every study.
- Use of the Distress Thermometer tool developed by Dr. Jimmie C. Holland should be encouraged. Dr. Walsh-Burke explained that this tool was used in studies that found that about 30 percent of cancer survivors were likely to evidence psychosocial distress severe enough to warrant intervention. The tool measures not only depression and anxiety symptoms, but also financial distress. An important part of any assessment tool is ensuring that socioeconomic factors are identified.
- Cost/benefit studies of psychosocial services should be conducted to address the issue of identifying who needs the service, determining the most effective way to deliver that service, and demonstrating its benefit. Few psychosocial interventions qualify as well controlled, and few randomized clinical trials include psychosocial interventions. One-quarter to one-third of all patients will manifest enough symptoms for psychosocial services to be considered, although the majority of those individuals will not need substantial intervention.
- Funding sources must be identified to meet critical needs. Unfunded mandates go nowhere. People want the Federal Government or the state to pay, but they do not want to pay more

taxes. People want insurance to cover services but do not want insurance premiums to increase. Finding alternative resources to meet priority needs is critical.

- Psychosocial support must be integrated into the oncology management system. Existing models for supporting psychosocial services for cancer patients and survivors should be identified. The larger health community is advocating psychosocial support as a part of comprehensive care. Historically, the health community has attempted to get psychosocial services covered by insurance. For example, nutritionists want insurance to cover their services so that it is easier for physicians and other health professionals to refer patients. Patients are more likely to use services that they do not have to pay for out of pocket. However, new, non-insurance funding resources should be found.

Recommendation Three

Public and private insurers should provide reimbursement for risk assessments, surveillance, and other follow-up care for cancer survivors, including care provided by appropriately trained non-physician personnel.

Key Points

- Insurance companies should be approached from a business perspective and be provided with evidence that they will benefit from adding coverage. It is important to demonstrate how an insurance company can save money and decrease financial risks by covering quality care.
 - Conduct a study of how health insurance affects time to diagnosis and determine whether delayed diagnoses result in more expensive care with higher morbidity and mortality rates. According to a study conducted by a graduate student from Baylor (now at M. D. Anderson), other than the type of cancer, insurance was the main predictor of the time it took to be diagnosed. The study examined time to diagnosis for 235 newly diagnosed 15 to 30 year olds with previously untreated cancer. This study should be expanded to see whether this finding is true at the national level and to tie that finding to the financial costs of delayed diagnoses.
 - Involve an economist in showing the insurance industry and governmental insurers that it would be cost-effective to insure young adults for cancer. Cost savings could be demonstrated by studying groups that have Government-provided health insurance. For example, one could compare the health care costs for AYAs who are covered by the U.S. military's health insurance or the Canadian or U.K. national health insurance systems with those of an AYA population that has standard insurance coverage.
- Cost-effectiveness of these services must be demonstrated. Strong evidence is needed to show that these services reduce health care utilization or health care-associated costs and improve functional outcomes and performance in individuals who receive them.
- Non-insurance solutions such as navigation, access, advocacy, and awareness programs have a role to play in implementing the Panel's recommendations. LAF and the CEO Roundtable programs provide excellent examples. LAF has been successful in engaging the community, assessing the needs of the survivors, creating a program to meet those needs, funding that program, and assessing its effectiveness. The CEO Roundtable's *Cancer Gold Standard* addresses cancer screening, cancer prevention, healthy lifestyles, and clinical trials.
- The existing cooperative group system could be expanded to track the follow-up services described in this recommendation. Dr. Comis described the cooperative group system's built-in program for monitoring people during and after their treatment through its robust database. The system offers a well-defined patient population of about 25,000 patients a year who could be followed for years. Additional resources would be required to add these services to the tracking program.

- The cost-effectiveness of follow-up care provided by nurse practitioners, social workers, and other non-physician personnel also must be demonstrated.
- Replicate the best-practice insurance models that have worked for young adults. Some insurers do a better job than others of covering prostheses; for example, Aetna has a good plan.
- CMS must be a leader in making coverage changes; other insurers may then agree to the same changes. A company-by-company approach to addressing coverage issues would require considerable time and work.
- The status and training of nurse practitioners should be more formally defined with respect to reimbursement. According to Dr. Weiner, nurse practitioners increasingly are the deliverers of care for survivors.

Recommendation Four

Fertility preservation procedures and infertility treatment services should be covered by health insurance for cancer patients/survivors whose fertility will be or has been damaged by cancer treatment.

Key Points

- Fertile Hope is evaluating approaches to establishing mandates or passing legislation requiring insurance coverage of fertility preservation and infertility treatment services. The organization considered a state-by-state approach to changing the way infertility was defined in such legislation. In this way, the benefits would not change but, rather, would become applicable to a larger or different group of people. Ms. Beck said Fertile Hope had expected the infertility organizations that had gotten the original legislation enacted would be allies in this process; instead, the other organizations feared that a push to change the infertility criteria would put the existing mandates at risk of being overturned.
- Existing legislation that covers infertility in noncancer settings should be reviewed before making cancer a special case. Fertile Hope has been advised to look at successful models such as Medicaid or the Federal Employee Health Benefits program. Ms. Beck asked for input and invited participants to commit to collaborating with Fertile Hope in its efforts.

RECOMMENDATION FIVE—FOLLOW-UP CARE MODELS

Participants were asked to address this final recommendation independently.

- Existing follow-up care clinic models should be evaluated and compared to ascertain their impact on survivor outcomes and their cost effectiveness.

Key Points

- LAF is building a network of survivorship clinics that can evaluate programs, accrue data more quickly, share those data, determine best practices, and share those practices throughout the network. The goal is to collect the information and translate it into practice quickly. LAF has funded six clinics to date. A network of centers is the optimum place to gather evidence that follow-up improves outcomes and determine which follow-up activities work best.
- There is a push-pull between providing needed services and care and developing an infrastructure for a network of interrelated centers that can conduct large-scale research.
- One of the primary infrastructure pieces of these centers is funding the salaries of advanced practice nurses and program directors who actively search medical records and call survivors to return for follow-up. Locating these survivors is a time-consuming, costly process. The young adult population does not want to take a day off work to travel back to those centers.

- It is critical that survivorship legislation include funding for evaluations of new and existing clinics.
- One issue is evaluating the clinic models; the second issue is cost effectiveness. This can depend on the location and the setup of the system. At Dana-Farber, insurance reimburses for diagnostic or screening tests that survivors need but does not cover psychosocial care. Coverage depends on the location, the insurance dynamic, and whether the survivor receives that care in the system or in the community.
- Study designs need to include a dissemination phase, moving results from independent, standing protocols or research into existing delivery systems. For example, LAF and the NCI are both funding studies of the impact of physical activity and exercise on outcomes among different populations of survivors. These studies will provide the evidence base needed to establish what works; the next step is disseminating and duplicating successful models.
- CDC is in a good position to disseminate and deliver interventions and practices for which there is evidence of efficacy. The CDC-funded state health department network is in place for delivery.
- Annual conferences provide another opportunity for dissemination of effective models.
- Legislative and regulatory provisions should include the broadest possible age range of cancer survivors who are eligible for follow-up services. Dana-Farber has accomplished this, which has meant a lot to patients and their families.
- Considerable attention has been paid to the special needs of cancer patients who contract cancer as children and young adults, but older adult patients have great need of follow-up due to comorbidities, especially because they may or may not be Internet literate.
- Many older adults, including cancer patients, fail to access services that are already available within their communities. Better methods are needed to inform older adults about such services and point them in the right direction to receive appropriate services.
- Primary care doctors need to be educated about comorbidities as well as about life after cancer and the medical consequences.
- In the next 18 months, NCI will have more data about where people are receiving their follow-up care and where NCI may need to consider directing its outreach or develop special programs specific to the older population of survivors.

ORGANIZATIONAL COMMITMENTS— RECOMMENDATIONS ONE THROUGH FIVE

Key Points

- The NCI will continue to pursue and support an evidence-based research agenda addressing this area.
- LAF will continue providing information and resources to help cancer survivors experience the highest quality of life possible.
 - LAF will continue to bring together partners who work with cancer survivors (e.g., AOSW and Patient Advocate Foundation) to help create informational content that is appropriate to the health literacy levels of cancer survivors and that describes some of the physical, emotional, and practical challenges survivors are likely to experience as a result of their cancer and its treatment.
 - LAF will continue to build information and referral resource networks, particularly involving access to financial resources, insurance coverage, and legal assistance. For example, LAF works with the New York Legal Assistance Group, which assesses the

cancer care-related legal needs of underserved populations and provides interventions to help them gain access to needed resources. LAF is committed to continuing that effort and to bringing together other community-, state-, and national-level groups that also provide those resources.

- LAF will establish an ongoing network of organizations, institutions, and professionals who are delivering these services so that, following the example of the survivorship clinics, this network can build tools and allow clinics to learn from one another's processes.
- LAF has set up a patient navigation program with CancerCare and Patient Advocate Foundation called the LIVESTRONG SurvivorCare. Cancer survivors contact LAF, go through an intake process, and are referred to resources that provide ongoing psychosocial support and patient navigation to access financial, legal, and insurance support. LAF is committed to continuing to enhance that patient navigation system.
- Fertile Hope is committed to ensuring that all patients are informed about cancer- and cancer-treatment-related fertility loss and fertility preservation options.
 - Fertile Hope is willing to do whatever it can in the research arena. The organization is currently working with scientists around the world to implement the objectives developed at the NCI-supported *Parenthood After Cancer* conference. Although Fertile Hope is a small organization and cannot fund those efforts, it is committed to helping in any way it can, including engaging patients to participate in research.
 - Fertile Hope is committed to the short-term financial assistance program and would welcome any collaboration and commitment from other organizations represented at the Panel meeting.
- The Children's Cause for Cancer Advocacy is committed to the education of the young population. The organization will conduct three to four workshops in the coming fiscal year in partnership with local programs, clinics, and grassroots organizations to provide face-to-face education to childhood and young adult cancer survivors. The Children's Cause will commit to developing adoptable legislation.
- The Children's Cause for Cancer Advocacy will continue to focus on families of survivors (whether they are children, adolescents, or adults) and is committed to partnering with people, working with grassroots organizations, and ensuring that there is advocacy on behalf of the cancer survivors.
- AOSW will continue to collaborate with other groups. AOSW is seeking funding for a new initiative to conduct the first comprehensive survey of its membership to identify the experts and those people who have developed models for the topics discussed at this meeting. For example, AOSW, which shares goals with Fertile Hope, will identify members who can help inform and engage in advocacy efforts. This will enable AOSW to collaborate more effectively with key groups like the National Coalition for Cancer Survivorship and LAF.
- Patient Advocate Foundation receives direct calls from patients and collects and analyzes the data obtained. The Foundation will gladly share that database, as well as its 2004 data analysis, with other organizations.
- Patient Advocate Foundation will continue to seek ways to increase funding support for AYA cancer patients. One of its immediate goals is to secure Medicaid support for adolescents and young adults diagnosed with cancer, at the point of diagnosis.
- The Ulman Cancer Fund is developing a caregiver guidebook; a large percentage of the young adults it interacts with are caregivers.

- The Ulman Cancer Fund will continue to collaborate on the LAF LIVESTRONG Young Adult Alliance initiative and focus on patient navigation systems aimed at the young adult population.
- As a research institution, Dana-Farber is strongly committed to survivorship and will continue to provide access to services, including psychosocial services, to any survivor and evaluate the impact of those services. Dana-Farber plans ongoing evaluations of cost-effectiveness, quality of life, and patient satisfaction.
- The Children's Oncology Group is committed to collaborations on survivorship research. COG has a goal to conduct survivorship transition research that focuses on empowering young adults to obtain appropriate survivorship care.
- The Coalition of Cancer Cooperative Groups (CCCCG) has considerable experience with surveys and can help by delving into its database.
- The CDC has not been particularly visible on the clinical side of the cancer question, but that is going to change.
 - CDC is committed to participating in the delivery of evidence-based practices that improve public health and the delivery of public health messages. The Division of Cancer Prevention and Control will focus on clinic models with respect to survivorship and psychosocial interventions.
 - CDC will continue to work with partner organizations such as LAF, ACS, and the NCI to explore the feasibility of novel public health approaches (e.g., collaboration with the New York Legal Assistance Group).
 - CDC is committed to conducting studies and demonstration projects that will answer questions about the potential public health impact of proposed interventions. It is CDC's intention to be a good partner in the effort to reduce the nation's burden of cancer.

PUBLIC COMMENT

Anna T. Meadows, M.D., Professor of Pediatrics and Medicine, University of Pennsylvania

- Transition clinics are needed for survivors of childhood cancer who are now young adults. These young adults need services provided by individuals who understand the risks of the treatment they underwent. These service providers must be knowledgeable and able to communicate information to patients in a way that is not frightening, is sensitive to their needs, and provides them with goals for staying well for the rest of their lives.
- Survivorship clinics tend to be either research-oriented or care-oriented, but not both. Research requires enrolling individuals from the target population. For example, a study on the effects of radiation on the heart should involve studying children with the same disease who did not have radiation to the heart. This kind of study is not reimbursable; it must be funded with research grants.

Archie Bleyer, M.D., Medical Advisor, St. Charles Medical Center; Director, AFLAC Research Projects in Adolescent and Young Adult Oncology, Children's Oncology Group

- The United Kingdom, through its National Institution for Clinical Excellence, announced that it is investing £14 million in the creation of cancer care units for adolescents. The U.K. will double the number of clinics because the first seven or eight (funded from private sources) were successful. Their efforts will provide a model for the United States to create similar facilities.

Kevin Oeffinger, M.D., Director, Living Beyond Cancer: A Program for Adult Survivors of Pediatric Cancer, Memorial Sloan-Kettering Cancer Center

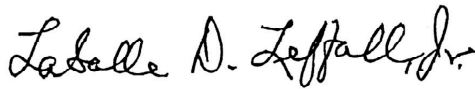
- It is important to study late effects in the long-term follow-up programs, which will allow for the definition of the types of problems survivors have and the determination as to whether these problems are modifiable or preventable. The next step is to disseminate that information and work with the communities—not only primary care physicians, but also ancillary health care service providers and subspecialists such as obstetricians and cardiologists.

Steve Friedman, Program Manager, Protocol and Information Office, CTEP, Division of Cancer Treatment and Diagnosis, NCI

- Insurance denials must be addressed because some services or treatments are defined as experimental therapy. Some of the greatest successes in cancer treatment are the result of off-label usage, investigational usage, and experimental therapy. The insurance industry must also change its thinking about preexisting conditions.
- Specific needs of cancer patients must be considered when prescribing physical exercise. Exercise has been shown to improve a person’s mental health, which is a tremendous benefit, but it is usually prescribed for healthy people. When prescribing exercise for cancer patients, attention must be paid to their specific needs (e.g., side effects of chemotherapy, radiation, and surgery).
- Expand the Panel’s discussions on insurance to include life insurance issues. It is extremely difficult for a cancer survivor to obtain life insurance, much less insurance that is affordable. Insurance actuaries ask only whether an applicant has had cancer; they do not distinguish between the types of cancer or the treatment received, the stage at which the cancer was diagnosed and treated, or how long an applicant has survived.

CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President’s Cancer Panel meeting, *Assessing Progress, Advancing Change: Challenges in Cancer Survivorship*, held August 26, 2005, is accurate and complete.



Certified by:

Date: January 23, 2006

LaSalle D. Leffall, Jr., M.D., F.A.C.S.
Chair
President’s Cancer Panel