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The NCI Director's Consumer Liaison Group (DCLG) hosted a successful Town Hall Meeting for advocates on the first evening, June 19, 2006, of the *Listening and Learning Together: Building a Bridge of Trust* Summit.

The purpose of the Town Hall Meeting was to give the DCLG an opportunity to listen to consumer advocates as they voiced their issues and concerns. Following the Summit, DCLG members decided they wanted to respond to what they heard.

We, the DCLG members, want the advocates who attended the Town Hall Meeting to know that we appreciated your presence and your willingness to give your constituents a voice at the Summit. We listened and learned from each of you! As advocates and DCLG members, we support the areas of research mentioned at the meeting. This document contains a range of questions posed at the Summit and responses that were assembled by the DCLG from resources NCI makes available to the public.

ADVOCACY ISSUES:

- Many of your groups are asking for a seat at the table.**
- Many of you asked where to go, whom to call to have more input and to obtain information.**
- Many of you said that a better understanding of the science will enable you to be better legislative advocates.**
- Many of you asked to have the role of advocates at NCI clarified.**
- Many of you expressed an interest in and a willingness to aid NCI's communication by placing information or questions on your group's Web site, but you don't know what NCI would like advocacy groups to post.**
- Many of you recommended that DCLG/NCI/OLA have more summits.**

The DCLG was honored to have the opportunity to bring together this diverse group of advocates. Many of you wanted the DCLG to be aware of what's on the combined cancer advocacy community's mind. We heard you loud and clear. As advocates ourselves, DCLG members are keenly aware of the issues and concerns brought forth at the meeting.

Many of the questions raised by advocates suggested a real commitment to learn more, not only about the DCLG, but also about the National Cancer Institute's mission and goals. Above all, advocates said they wanted to be involved by being a voice for their communities.

The DCLG urges advocates to participate by learning about the services available to them through NCI's Office of Liaison Activities (OLA). OLA supports NCI's research and related programs by fostering strong communications and relationships with the cancer advocacy community and professional societies. In fact, OLA coordinated the *Listening and Learning Together* Summit with the DCLG's guidance.

We encourage you to visit OLA's Web site at <http://ola.cancer.gov> where you can find multiple opportunities to get involved: attend public meetings, provide comment on government policies, and listen in on toll-free teleconferences. The information is in the public domain and may be reprinted or reproduced in your organization's Web site or newsletter.

One way to become involved is to join the listserv to receive the *NCI Nealon Digest*. This biweekly electronic newsletter highlights the federal government's efforts to reduce the burden

of cancer. By signing up for this listserv you will also receive occasional messages about other opportunities to learn more about NCI's research mission. This information is also in the public domain and may be reprinted or reproduced in your organization's Web site or newsletter.

Another way NCI involves advocates is through OLA's Consumer Advocates in Research and Related Activities (CARRA) program. CARRA was created in September 2001 to provide a formal mechanism for consumer advocates who represent the patient viewpoint to participate in various NCI activities, such as peer review of grants on an as-needed basis. Current CARRA members have a 3-year term that will end in September 2007. The call for new applicants is advertised in the *NCI Nealon Digest*, mentioned above. Please visit <http://carra.cancer.gov> for more details. The <http://carra.cancer.gov/members/training/resources> Web site has links to much useful information for all advocates (not just CARRA members). You may also find a presentation on NCI's organization, mission, and budget to be of interest, available at <http://carra.cancer.gov/images/content/Pre-Workshop-Teleconference.pdf>.

OLA also administers the NCI DCLG. Launched in 1997, the DCLG—a federally chartered committee—was the first all-consumer advisory board at NIH. The DCLG's 16 members advise the NCI Director about a wide variety of issues, programs, and research priorities from the perspective of people whose lives are affected by cancer. OLA has created a DCLG Web page at <http://dclg.cancer.gov> that provides information on the group's charter, membership biographies, and member activities. Every year members rotate off of the DCLG and new members are selected by the NCI Director. Nominations for new members are sought early in each year, with applications due in March; further information on nominations will be posted in the *NCI Nealon Digest*.

We also encourage you to investigate a pilot online forum for dialogue with the advocacy community and the general public. NCI launched this Web site forum, *NCI Listens and Learns*, in which advocates and interested members of the public participate in an open dialogue with NCI on a range of cancer research topics. NCI posts discussion topics related to its programs and priorities, and both advocacy groups and members of the public are encouraged to provide feedback and help shape the direction of its future activities. The *NCI Listens and Learns* Web site can be viewed at <http://ncilistens.cancer.gov/>.

NCI also has a number of formal advisory boards, with public members on the National Cancer Advisory Board (NCAB), the Board of Scientific Advisors, the Board of Scientific Counselors, and the President's Cancer Panel. To learn more about all of these groups, visit <http://deainfo.nci.nih.gov/advisory/boards.htm>.

NCI is committed to communicating with the public and the research and medical communities about its mission, programs, and scientific progress. NCI works closely with the media, advocacy groups, and professional societies to disseminate this information. News releases and information on cancer can be found on the NCI Web site at <http://cancer.gov>. In addition, the site has information on clinical trials, statistics, research programs, and research funding, and you may subscribe free of charge to the *NCI Cancer Bulletin*, a biweekly electronic newsletter, to keep you abreast of NCI research news. Again, this information is in the public domain and may be reprinted or reproduced in your organization's Web site or newsletter.

The DCLG fully intends to recommend to the NCI Director that a future Summit should be scheduled for advocates.

☑ Why are publications limited to 50 copies at a time? We would like more.

Many people have access to the Internet and can view or download NCI publications, so a more economical way to disseminate information is through downloading them from the Web. Publication costs have soared in recent years as the budget has decreased. To accommodate the numerous requests, publication limits are set according to inventory supply and instructions by the NCI program staff that “owns” the publication. For example, most of the printed material from the Office of Education and Special Initiatives has a 100-copy limit per order. However, if the stock is low, the limit will most likely be lowered—depending on when staff plans to revise or reprint.

All NCI publications are in the public domain and may be reprinted or reproduced in your organization’s Web site or newsletter. For health fairs, advocacy groups are encouraged to make flyers listing NCI publication URLs or information on how to get copies by calling 1-800-4CANCER. For more information about ordering NCI materials, visit www.cancer.gov/cancertopics/factsheet/NCI/order-publications.

☑ Can advocates have bullet-point deliverables to share with Congress and others to help raise research money? Dollars saved? Stories of heroes? Researchers? How can we make it interesting/attention grabbing for legislators?

NCI’s Office of Science Planning and Assessment provides disease-specific snapshots that include up-to-date information on trends in incidence, mortality, and NCI funding; distribution of NCI projects by Common Scientific Outline or type of research; and relevant NCI initiatives. Adobe Acrobat Reader is required to view these documents, located at <http://planning.cancer.gov/disease/snapshots.shtml>. During 2007, NCI is celebrating 70 years of research excellence. You may want to visit the commemorative Web site at www.cancer.gov/aboutnci/ncia to view more information about NCI and more than 100 years of advances against cancer. All articles from the *NCI Cancer Bulletin*, *NCI Nealon Digest*, or <http://cancer.gov> are in the public domain and may be reprinted.

NCI is developing a series of brief fact sheets entitled, “Cancer Advances in Focus.” These fact sheets, available on www.cancer.gov, focus on specific cancers and highlight ways in which research has reduced their burden and improved quality of care.

- ☑ How can advocates interface with legislators?**
- ☑ How can advocates improve their work at local, regional, and national levels?**
- ☑ How can advocates lobby for increased funding with budgets already stretched thin?**
- ☑ How can we recruit more minority advocates and train them, especially black men for prostate cancer advocacy?**
- ☑ Can cancer research centers be given a special label or credential for having a patient advocacy program?**

Many cancer-related organizations focus on various kinds of advocacy in the cancer community—legislative advocacy, research advocacy, patient advocacy, fundraising, support, and education advocacy, etc. Those interested in research advocacy most often work with NCI. Research advocacy offers an opportunity to enhance education, for a better understanding of research, and also to participate in peer review of scientific grant applications, in review of

educational materials, and on advisory boards, both locally and at the national level.

Many national advocacy groups sponsor training in various kinds of advocacy, with teleconferences and class sessions. Those interested should search the Web sites of various advocacy groups. NCI is required to follow federal law, which says the Institute cannot encourage any individual or organization to lobby Congress on its behalf. Here are examples of advocacy organizations that offer research advocacy training:

American Association for Cancer Research (AACR)

Scientist↔Survivor Program

This program is an opportunity to hear the latest clinical research findings. One unique feature is that survivors/advocates are paired with researchers and physicians to help with mutual understanding of issues in small group meetings and plenary sessions. There is also an opportunity to network with advocates from consumer organizations from around the world. This program is for all cancers, with international participation.

<http://www.aacr.org/home/survivors--advocates/scientistharr;survivor-program.aspx>

National Breast Cancer Coalition

Project LEAD

This program offers advocates a four-day course in biology and the epidemiology of breast cancer, taught by some of the most well known scientists and physicians in the field. At the end of this course, each advocate will have a basic understanding and general knowledge of research, drug protocols, and clinical trials.

<http://www.natlbcc.org/bin/index.asp?Strid=482&depid=7>

Research Advocacy Network (RAN)

Advocate Institute

The RAN Advocate Institute provides a means of directing the passion of patient advocates to more effective interactions with researchers through curricula, on-site presentations, and online learning opportunities. Visit www.researchadvocacy.org/ to learn more.

San Antonio Breast Cancer Symposium

Alamo Breast Cancer Foundation

Patient Advocate/Mentor Program

This program is designed to help advocates understand the latest findings in breast cancer research. Mentors clarify these findings and assist advocates in writing hot topic papers that are published after the meeting.

<http://www.sabcs.org/PatientAdvocates/index.asp>

We need more research on complementary and alternative medicines/therapies.

The Office of Cancer Complementary and Alternative Medicine (OCCAM) was established in October 1998 to coordinate and enhance NCI's activities in the arena of complementary and alternative medicine (CAM). The goal of OCCAM is to increase the amount of high-quality cancer research and information about the use of complementary and alternative modalities by:

- Promoting and supporting research on CAM disciplines and modalities as they relate to the prevention, diagnosis, and treatment of cancer, cancer-related symptoms, and the side effects of conventional treatments.
- Coordinating NCI's CAM research and information activities.
- Coordinating NCI's collaboration with other governmental and non-governmental organizations on CAM in cancer.
- Providing an interface with health practitioners and researchers on CAM as it applies to cancer.

To learn more about complementary and alternative medicine and its application to cancer research, please visit www.cancer.gov/cam/. For highlights of recent OCCAM activities, visit www.cancer.gov/cam/cam_sponsored_research.html.

Several opportunities have been made available for advocates to become involved with NCI's OCCAM efforts. These include the November 7, 2006, teleconference, "What Advocates Should Know About Complementary and Alternative Medicine," which featured Dr. Jeffrey White, Director of OCCAM. The *NCI Listens and Learns* Web site comment period in August 2006, gave advocates an opportunity to view CAM cancer information summaries. OCCAM also sponsors an ongoing lecture series.

Teleconference Series: <http://ola.cancer.gov/activities/teleconferences>.

NCI Listens and Learns Web site:

<http://ncilistens.cancer.gov/moderator.asp?action=discussion&discussion=63>.

- How can opportunities be created for orphan diseases/rare cancers to get together? Could DCLG facilitate a teleconference with NCI scientists and advocates? Set up a listserv?**

NCI does not have one office or division focused on rare cancers. Research on rare cancers is spread throughout the Institute. This makes bringing advocates together to discuss this topic unlikely and difficult. Many small conferences and workshops are held that focus on identifying gaps in knowledge and opportunities for future research.

However, the Office of Rare Diseases (ORD) was established in 1993 within the Office of the Director of the National Institutes of Health (NIH). On November 6, 2002, the President established the Office in statute (Public Law 107-280, the *Rare Diseases Act of 2002*). A rare disease (also called an orphan disease) is a disease or condition that affects fewer than 200,000 persons in the United States. An estimated 25 million people in the United States have such a disease, and based on this definition, many forms of cancer are considered rare.

The goals of ORD are to stimulate, support, and coordinate research on rare diseases in response to the needs of patients with one of the more than 6,000 rare diseases now known. To leverage its resources, stimulate rare disease research, and foster collaboration, ORD works with NIH Institutes and Centers to support:

1. A program that makes grants to establish a network for rare disease research, with a component to train rare disease investigators.
2. An intramural center for patients with undiagnosed rare conditions, and programs to stimulate clinical research on rare diseases and to train researchers interested in rare diseases.
3. A program to support scientific conferences that stimulate research where little exists, where progress has stalled, or in response to scientific opportunities.
4. Regional workshops to assist patient support groups in becoming partners with NIH, better understanding its research programs, and gaining better access to NIH research opportunities.
5. A center and other dissemination mechanisms to supply reliable and valid information to the public, researchers, and health care providers, including various databases to provide access on the Web and the ORD Web site.
6. A number of ancillary activities that contribute to furthering research on rare diseases.

For more information on ORD, please view

http://rarediseases.info.nih.gov/html/resources/about_ord.html.

ORD also issues an annual report describing NIH's research on these diseases. This report can be found at http://rarediseases.info.nih.gov/html/resources/rep_pubs.html.

For information on rare cancers, please contact the National Cancer Institute's Cancer Information Service (CIS) toll free at (800) 4-CANCER.

The National Organization on Rare Diseases also offers several services and programs for those suffering from such diseases. More information can be found at www.rarediseases.org.

Here are a few more links:

<http://rarediseases.info.nih.gov/>

www.genome.gov/10000409

http://rarediseases.info.nih.gov/html/resources/info_ctr.html

http://rarediseases.info.nih.gov/html/resources/news_conf.html

Below are links to proceedings of a previous NCI-specific workshop on rare cancers:

2nd NCI Epidemiology Leadership Workshop: Understudied Rare Cancers
Boston, Mass. September 11–13, 2005

<http://epi.grants.cancer.gov/Conference2/summary.html>

Panel Discussion: Rare Cancer Advocates and Survivors: The Few and Far Between

<http://epi.grants.cancer.gov/Conference2/summary.html#F1>

Session Chair: Julia H. Rowland, Ph.D.
Director, Office of Cancer Survivorship, DCCPS, NCI

Advocate Panelists:

- Douglas Bank
*President and Editor
Testicular Cancer Resource Center*
- Richard N. Boyajian, R.N., M.S.
*Lance Armstrong Foundation Adult Survivorship Clinic
Perini Family Survivors Center
Dana-Farber Cancer Institute*
- Cary Zahrbock
National Coalition for Cancer Survivorship

In this discussion, Dr. Rowland asked panelists to respond to a series of questions about the role of epidemiology in the life of cancer survivors and members of the public who have never had cancer.

Additional information on rare cancers is available through the following links.

Unusual Cancers of Childhood (PDQ) Treatment:
www.cancer.gov/cancertopics/pdq/treatment/unusual-cancers-childhood.

Other Rare Childhood Cancer: www.cancer.gov/cancertopics/pdq/treatment/unusual-cancers-childhood/Patient/page6.

Lab-On-A-Chip Device Isolates Rare Cancer Cells in Minutes:
http://nano.cancer.gov/news_center/nanotech_news_2005-10-24b.asp.

Who was William Natcher?

William H. Natcher was a Democratic representative from Kentucky who served in the U.S. House of Representatives from 1953 to 1994. A tireless supporter of biomedical research, he holds the record for the longest tenure ever served in Congress without missing a vote.

A conference center and administrative office building on the NIH campus is named in his honor. In fact, the Summit was held there. Building 45, the William H. Natcher Conference Center, includes office space for 600 extramural staff, a 1,000-seat auditorium, a state-of-the-art multi-use, multimedia Conference Center with nine conference rooms, a 300-seat cafeteria, and below-grade employee parking for 450 vehicles. It was completed in 1994.

How is the breast cancer stamp money handled, and is it kept separate from NCI funding?

The Breast Cancer Research stamp was first authorized by the *Stamp Out Breast Cancer Act* on August 13, 1997. Profits from the sale of the stamp fund breast cancer research, with 70 percent going to NIH and 30 percent to the Department of Defense. As of fiscal year (FY) 2005, NCI has received \$30,764,211 since the breast cancer stamp was first issued in 1998, which it has used to fund breast cancer research projects. Thus far, two major programs have been funded: the Insight Awards to Stamp Out Breast Cancer and the Breast Cancer Research Stamp Exception Program. In FY 2004, 10 awards were funded, totaling \$3.5 million from the breast cancer stamp, and in FY 2005, 7 awards were funded totaling \$4.4 million. Most recently NCI's Executive Committee voted to fund a Breast Cancer Premalignancy Program of research at NCI. For more information, please visit <http://olpa.od.nih.gov/legislation/109/publiclaws/breastreauthorization.asp> and www.cancer.gov/ncicancerbulletin/NCI_Cancer_Bulletin_020706/page9.

POLICY ISSUES:

- No screening dollars are available for some (e.g., Native Americans) and no access to care, especially for people in remote areas.**
- Who treats patients after free screening?**
- How can advocacy groups get support/funding?**
- Access to care for rural poor.**
- Assurance of confidentiality, no medical profiling, etc.**
- Insurance for everyone. Physicians for a National Health Program have a wonderful proposed program. Can the DCLG please study and endorse this?**

The DCLG consists of 16 advocates who work and interface with the cancer community throughout the United States. We are keenly aware of the issues faced by those yet-to-be-served communities who lack health insurance and access to health care services. However, these issues do not fall under the purview of NCI. The DCLG's mission is to advise the NCI Director on NCI's programs and initiatives. As DCLG members we cannot "endorse" a national insurance program. However, in our private capacities many of us support health insurance for all.

The U.S. Health Resources and Services Administration (HRSA) runs Health Centers that provide health and dental care to people of all ages, whether or not they have health insurance or the money to pay for health care. To find the Health Center nearest you go to <http://ask.hrsa.gov/pc/> and enter your state.

One funding source for screening certain cancers is the Centers for Disease Control and Prevention, which supports grants through states. Health care on the reservations of American Indians is very complex and inadequate. The Department of Health and Human Services' [Intradepartmental Council on Native American Affairs](#) ensures coordination and consultation on health and human services and on social and economic development issues affecting the American Indian, Alaska Native, and Native American populations. Please note that NCI funds research on the impact of these policy areas. Here are examples of NCI-sponsored research:

SPN Project Description: The Network for Cancer Control Research Among American Indian and Alaska Native Populations

Investigator: Judith Kaur, M.D.

Institution: Mayo Clinic Foundation, Rochester, Minn.

The Network for Cancer Control Research Among American Indian and Alaska Native (AI/AN) Populations was established to increase awareness and understanding about cancer in native communities, provide training in cancer control research for AI/AN researchers, and improve communication between the Native and research communities to encourage research focused on issues that affect Native people. The network addressed comprehensive tribal cancer control issues through partnerships with tribal cancer centers, the Cancer Information Service, and the American Cancer Society.

SPN Project Description: American Indian Initiative in Arizona

Investigator: Michael Lobell, M.D.

Institution: Arizona Cancer Center, Tucson, AZ

The goal of the American Indian Initiative in Arizona was to build a strong oncology program dedicated to addressing the cancer awareness, prevention, and early detection needs of Native Americans through mutual trust, cultural sensitivity, and tribal representation. The project was operated by the Arizona Cancer Center in partnership with the Phoenix Indian Medical Center (an Indian Health Service hospital). The geographic area served by the project is home to more than 100,000 members of more than 40 tribes ranging from the small Cocopah tribe in southwestern Arizona to the widely dispersed Paiute tribe in Nevada and Utah.

NCI's Center to Reduce Cancer Health Disparities addresses research in underserved populations in the Community Networks Program (<http://crchd.cancer.gov/cnp/cnp-project-listing.html>).

EDUCATION ISSUES:

- Suggestion: NCI should produce simple public service announcements that explain what clinical trials are. Helping people understand might help with enrollment.**
- Can NCI help change the term from “clinical trial” to “clinical study”? People are afraid of the word “trial.” There are still people out there who believe they will receive a placebo and no other treatment—no wonder accruals are so low.**
- How can you get into a clinical trial if the company eliminates you prior to the start because you aren't sick enough?**

Realizing that clinical trial participation is extremely low, we are happy to report that the NIH Office of Communications and Public Liaison in the Office of the NIH Director is developing a major clinical trials campaign to enhance public knowledge about clinical trials.

It would take a major overhaul of the clinical trials enterprise to change the term “clinical trials” to something else. However, this idea has been raised before. It is our hope that more public education will help people understand clinical trials better.

We admit it is difficult to be denied access to a clinical trial when you do not meet the specific criteria. However, to have accurate research findings in the discovery of new and effective cancer drugs, scientists require participants to meet the letter of the written clinical trial protocol. Without these parameters in place, how could a researcher determine if the medicine or therapy worked in the targeted population?

NCI produces consumer-friendly clinical trial educational materials, available at:
<http://www.cancer.gov/clinicaltrials/learning>.

I have heard cervical cancer referred to as a sexually transmitted disease. When during prevention do you feel it is appropriate to approach it as such?

The Food and Drug Administration (FDA) announced on June 6, 2006, the approval of Gardasil, the first vaccine developed to prevent cervical cancer, precancerous genital lesions, and genital warts caused by human papillomavirus (HPV) types 6, 11, 16, and 18. The vaccine is approved for use in females aged 9–26 years. Gardasil was evaluated and approved in six months under FDA’s priority review process—intended for products with the potential to provide significant health benefits. Early research sponsored by NCI laid the groundwork for this vaccine.

HPV is the most common sexually transmitted infection in the United States. The Centers for Disease Control and Prevention estimates that about 6.2 million Americans become infected with genital HPV each year and that over half of all sexually active men and women become infected at some time in their lives. On average, there are 9,710 new cases of cervical cancer and 3,700 deaths attributed to it in the United States each year. Worldwide, cervical cancer is the second most common cancer in women, with an estimated 470,000 new cases and causing 233,000 deaths each year.

For most women, the body’s own defense system will clear the virus and infected women do not develop related health problems. However, some HPV types can cause abnormal cells on the lining of the cervix that years later can turn into cancer. Other HPV types can cause genital warts. The vaccine is effective against HPV types 16 and 18, which cause approximately 70 percent of cervical cancers and against HPV types 6 and 11, which cause approximately 90 percent of genital warts.

For more information, visit www.fda.gov/bbs/topics/NEWS/2006/NEW01385.html.

RESEARCH PRIORITIES AND ISSUES:

- Confidentiality issues—no medical profiling.**
- Emphasis on cultural diversity.**

These are issues we as DCLG members consider as of the utmost importance. At our meetings we have deliberated the need for legislation prohibiting discrimination based on biomedical discoveries on genetic factors for risks of cancer and other serious illnesses. In addition, we have often discussed confidentiality and the need for cultural diversity as we listen to presentations and consider topics ranging from clinical trials to tissue banking.

The mission of NCI is to improve human health through biomedical and behavioral research. Research involving human participants is a necessary and important part of that mission. Therefore, NIH is committed to assuring that all of its research involving human participants promotes their rights and welfare.

For a guide on understanding informed consent, please view www.cancer.gov/clinicaltrials/conducting/informed-consent-guide.

To learn more about the numerous ways in which NCI protects participants involved in clinical trials, please view www.cancer.gov/clinicaltrials/digestpage/protecting-participants.

- We would like to see more emphasis on healing (survivorship issues?).**
- Psychosocial research. How can support groups be emphasized as an important adjunct to active and post-therapy survivors?**

NCI considers an individual to be a survivor from the time of diagnosis through the balance of his or her life. Because friends, family members, and caregivers are also affected by a cancer diagnosis, they are included in this definition. NCI's Office of Cancer Survivorship (OCS) was established in July 1996 in recognition of the large number of individuals now surviving cancer for long periods of time and their unique and poorly understood needs.

OCS supports and promotes research that examines and addresses the long- and short-term effects of cancer and its treatment. These include physical, psychological, social, and economic effects among pediatric and adult survivors and their families. Survivorship research focuses on the physical, emotional, social, and financial outcomes, beyond the treatment phase, and seeks to optimize the health and well-being of persons living with a history of cancer. Survivorship research also seeks to provide a knowledge base regarding optimal follow-up care and surveillance of new or recurrent cancers.

Research supported by OCS focuses on many aspects of survivorship. The primary areas of research include:

- Chronic and late effects of cancer and its treatment.
- Interventions.
- Healthy lifestyle and behaviors.
- Benefit finding and posttraumatic growth.
- Family.

To learn more about the research supported and promoted by the Office of Cancer Survivorship, visit http://dccps.nci.nih.gov/ocs/research_areas.html or <http://dccps.nci.nih.gov/ocs/>.

Ending cancer treatment can be both exciting and challenging. Most people are relieved to be finished with the demands of treatment, but many also feel sadness and worry. Many are concerned about whether the cancer will recur and what they should do after treatment. Tools for survivors and their families can be found on the Office of Cancer Survivorship Web site at <http://survivorship.cancer.gov>. There you will find links to such resources as *Facing Forward: Life After Cancer Treatment*, *Siga adelante: la vida después del tratamiento del cancer*, and *Ways You Can Make A Difference in Cancer*. These booklets provide a concise overview of survivor issues post-treatment, such as ongoing health needs, how to deal with your feelings, insurance, and employment, and information on getting involved with cancer-related activities. To view the *Facing Forward* series, visit www.cancer.gov/cancerinfo/life-after-treatment.

- We need more research on palliative care and end-of-life issues.**

Globally, an estimated 22.4 million people are living with a history of cancer, with more than 10.5 million cancer survivors in the United States. The field of palliative care, once largely

confined to providing comfort to the dying, has broadened to include the physical, social, psychological, and spiritual aspects of coping with cancer over the entire continuum of cancer care. This change in perspective is due in part to medical advances that have resulted in more people experiencing cancer as a chronic disease.

Research on palliative care and end-of-life issues is supported by the NCI Division of Cancer Prevention: See www.cancer.gov/prevention/coprtrg/supportivecare/index.html.

Please view www.cancer.gov/newscenter/benchmarks-vol3-issue4/page1.

NCI's Physician Data Query (PDQ) series provides descriptions of the pathophysiology and treatment of common physical and psychosocial complications of cancer and its therapies. The series also includes PDQs on nutritional and emotional concerns, late-term effects, survivorship, and end-of-life issues.

Please view www.cancer.gov/cancertopics/coping/.

More research is needed on prevention (not just early detection).

Scientists estimate that as many as 50 percent to 75 percent of cancer deaths in the United States are caused by human behaviors such as smoking, physical inactivity, and poor dietary choices. The following behaviors or changes in behavior can help prevent cancer:

- Not using cigarettes or other tobacco products.
 - Age at smoking initiation
 - Youth smoking
 - Adult smoking
 - Quitting smoking
 - Doctors' and dentists' advice to quit smoking
- Not drinking too much alcohol.
- Eating five or more daily servings of fruits and vegetables.
- Eating a moderate-fat diet.
- Consuming a diet in which total calories eaten are balanced with calories expended in physical activity.
- Maintaining or reaching a healthy weight.
- Being physically active.
- Protecting skin from sunlight.

NCI has an entire Division focused on prevention. Please visit the Division of Cancer Prevention (DCP) Web site at <http://www.cancer.gov/prevention>. NCI has a division with an entire program focused on behavioral science. Please visit the Division of Cancer Control and Population Sciences (DCCPS) Web site at <http://www.cancercontrol.cancer.gov>.

In *The Nation's Investment in Cancer Research: A Plan and Budget Proposal for FY 2006*, strategic investments were made in cancer prevention, early detection, and prediction. The goals are to substantially reduce the incidence of cancer, to integrate early detection with markers of prognosis through the development and effective delivery of medical approaches to prevention and early detection, and to promote effective, evidence-based public health interventions and policies.

Newly aligned goals focused on preventing cancer and detecting it early when it is most curable are at the heart of our nation's research and public health agendas. Dramatic developments in technology and a more complete understanding of the causes and mechanisms of cancer will enable NCI to provide more effective ways to prevent the disease. New evidence-based interventions encourage lifestyle improvements in diet and physical activity, discourage smoking, and promote the use of safe and fully tested chemoprevention approaches for people at risk. Pioneering proteomic and biomarker advances and the promise of nanotechnology give new hope for the early detection and diagnosis of cancer and prediction of patient response to treatment. Advanced information systems and methods of evaluation will maximize the impact of existing technologies. NCI is ramping up specimen repositories and widely accessible bioinformatics resources to support the development of these breakthroughs.

Please view <http://plan2006.cancer.gov/prevention.shtml>.

To view the *Cancer Trends Progress Report*, see <http://progressreport.cancer.gov/doc.asp?pid=1&did=2005&mid=vcol&chid=21>.

To view recent developments in cancer prevention, see <http://www.cancer.gov/clinicaltrials/ct-types-list>.

What will be the impact on women if research moves away from site-specific cancers?

On both the NIH and the NCI levels, scientists continue to focus on basic research, which may have implications for many diseases, and site-specific research, which is focused on a specific disease process. NCI's strategic planning process is not directed at specific cancers, but toward broad-based science that could have an impact on all cancers in all populations.

NCI supports a number of broad-based research programs that apply to all types of cancer in both women and men. Through its strategic planning process, NCI has identified many of the questions that need to be answered, areas of research and care that need to be supported, and infrastructure that needs to be strengthened to reduce the burden of cancer in all populations. The NCI Strategic Plan, (<http://strategicplan.nci.nih.gov/>), released in 2006, describes eight strategic objectives in two broad areas, *To Preempt Cancer at Every Opportunity* and *To Ensure the Best Outcomes for All*. NCI supports research programs to expedite progress toward these objectives.

In addition, please view *NCI's Annual Plan and Budget Proposal for Fiscal Year 2008*, <http://planning.cancer.gov/planning/budget.shtml>.

Young survivor research. What research is being conducted for young adults (aged 15–39 years) with cancer? For example, treatments, diagnosis, fertility, prevention, and education.

Relatively little is known about biologic, genetic, epidemiologic, therapeutic, psychosocial, and economic factors that affect the incidence, disease outcomes, and quality of life of adolescents and young adults (AYAs) diagnosed with cancer. However, it is known that compared with younger and older age groups, this population—defined as those diagnosed with cancer at ages 15 through 39—has seen little or no improvement in cancer survival rates for decades.

The first monograph to collect detailed information about cancer incidence and outcomes in adolescents and young adults was published in 2006 (<http://seer.cancer.gov/publications/aya/>). It was developed to gather population-based incidence, mortality, and survival data specific to cancers that occur in the AYA population, along with epidemiological data and risk factors for the development of age-specific cancers. Prepared by NCI's SEER Program and the Children's Oncology Group (COG), with special assistance from the Adolescent and Young Adult (AYA) and Epidemiology Committees, volunteer editors and authors from NCI, NCI-sponsored adult cancer cooperative groups (Southwest Oncology Group, Eastern Cooperative Oncology Group, Cancer and Leukemia Group B, National Surgical Adjuvant Breast and Bowel Program, American College of Surgeons Oncology Group), and NCI-designated Comprehensive Cancer Centers, this monograph will help educate medical providers and the public about cancer incidence and survival in this age group, and provide the impetus for further research to improve their survival and quality of life.

In 2005–2006, NCI partnered with the Lance Armstrong Foundation (LAF) to convene an Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG) to assess the special research and cancer care needs of the AYA age group and solicit recommendations for a national agenda to improve cancer prevention, early detection, diagnosis, treatment (including survivorship care), and outcomes among these patients. This AYAO PRG brought together more than 100 experts from diverse disciplines across the research and cancer control enterprise and the advocacy and survivor communities. Their principal focus was on identifying priority interventions for improving the outcomes of people diagnosed with cancer as adolescents and young adults and they made five recommendations. To view the full report, see http://planning.cancer.gov/disease/AYAO_PRG_Report_2006_FINAL.pdf.

An AYAO research portfolio analysis prepared for PRG purposes showed 235 distinct projects relevant to AYAO research from fiscal years 2002 through 2005. Of these, 108 were funded by NCI and 127 by other organizations that contribute data to the [International Cancer Research Portfolio](#) and the Lance Armstrong Foundation. The number of AYAO research projects increased during these years for all organizations.

The AYAO PRG suggested that a major research initiative emphasizing clinical trials and outcomes research was urgently needed. Collaboration and support from numerous governmental, academic, public health, community-based, and private sector entities will be essential to this initiative's success.