

June 2007

In This Issue

- Research 1
- Education. 1
- Training 6

Partners



HPNA



The National Cancer Institute (NCI) supports initiatives in research, education, and training to improve symptom management and palliative care in cancer. This annual update is to inform our colleagues, partners, and advocacy communities about our activities and encourage further collaborations and information exchanges where possible.

Research

Symptom Management & HRQOL Scientific Steering Committee Formation

In January 2004, the Director of the NCI established the Clinical Trials Working Group (CTWG) to advise the National Cancer Advisory Board (NCAB) on ways in which to restructure the national clinical trials enterprise. (http://integratedtrials.nci.nih.gov/ict/CTWG_report_June2005.pdf).

A key scientific priority of the CTWG plan was to “Establish a funding mechanism and prioritization process to ensure that the most important correlative science and quality of the life studies can be initiated in a timely manner.” In response to this priority, the NCI has established the Symptom Management and Health-Related Quality of Life (SxQOL) Steering Committee (SC), which will

prioritize and review the symptom management clinical trials conducted through the CCOP Research Bases and the secondary quality of life endpoints in the phase III Cooperative Group cancer treatment trials. Members include representatives from the CCOP Research Bases, Cooperative Groups with HRQOL Committees, NCI scientists, community investigators, patient advocates, biostatisticians, psychometricians, and R01 investigators. The first face-to-face meeting is scheduled for summer 2007 and information about the SxQOL SC will be made available under the Steering Committee section of the NCI’s Coordinating Center for Clinical Trials Web page at: <http://ccct.nci.nih.gov/>.
(continued on page 2)

Education

NCI’s Cancer Information Service (CIS)



The CIS revised and implemented an updated version of their psychosocial and survivorship

training module to expand information on end of life issues. This revised module will enhance Information Specialists’ ability to provide palliative care information to those who contact the CIS. *(continued on page 4)*

Research

(continued from page 1)

Update on Reducing Barriers to Palliative Care RFA Grantees

On September 25, 2006, the NCI held the first meeting of R01 grantees. The purpose of the meeting was to discuss progress and issues. A major theme among the grantees was the challenge to recruiting participants. Dr. Ferrell took the lead and designed a survey that focused on the many issues and challenges to recruiting participants and was sent to all the RFA grantees. We are currently analyzing the data, and the goal is to publish the findings. The next meeting will be held in late September 2007 and will include both R01 and R21 grantees. Symptom management and palliative care grantee abstracts are available at: <http://prevention.cancer.gov/programs-resources/groups/copt/programs/active>.

Symptom Management and Supportive Care Studies

Supportive care research includes the primary and tertiary prevention of both cancer and treatment associated morbidities. This includes research on the management of acute symptoms related to cancer and its active treatment during the treatment phase and at the end of life. Currently, NCI is supporting over 100 studies in this broad area through a variety of funding mechanisms (cooperative agreements, planning grants, and investigator-initiated grants). One of the major funding mechanisms is the cooperative agreement that supports the Community Clinical Oncology Program (CCOP), a network for conducting cancer prevention and treatment clinical trials by community medical practitioners. This network connects academic centers (Research Bases that design and conduct the trials) with community physicians (CCOP, MB-CCOP) who accrue patients to those trials. The CCOP Research Bases that design symptom management studies include NCI-designated Cancer Centers and NCI-sponsored Clinical Trials Cooperative Groups. For a complete listing of these studies, go to: <http://prevention.cancer.gov/clinicaltrials/ongoing/supportivecare>.

Patient-Reported Outcomes Assessment in Cancer Trials (PRO ACT)

On September 20 and 21, 2006, the NCI and the American Cancer Society co-sponsored an international conference, *Patient-Reported Outcomes Assessment in Cancer Trials: Evaluating and Enhancing the Payoff to Decision Making*. The three objectives of the PROACT conference were to: identify when, where, and how PRO assessment brings significant value to a clinical trial; develop guidance for the cost-effective conduct of PRO assessment in trials, in order to maximize useful information while limiting patient and provider burden in collecting such data; and identify research studies and application projects that would enhance the decision-relevance of health-related quality of life (HRQOL) and symptom measurement in cancer clinical trials. A fourth objective of the PROACT conference was to identify critical issues for



implementing PRO research in NCI-sponsored clinical trials, including those being addressed by NCI's newly established Steering Committee on Symptom Management and Quality of Life (SxQOL) research.

By synthesizing the results from case studies presented at the meeting, experts from the conference began to identify “best practices” for the application of PRO measures to ensure that the most important HRQOL studies can be initiated in a timely manner in association with NCI-sponsored clinical trials. These case studies and the findings from this conference will be featured in the *Journal of Clinical Oncology* in November 2007. Conference presentations are available on the NCI Web site: <http://outcomes.cancer.gov/publications/workshops/proact/>.

Integrating PROs in Clinical Oncology Practice

The NCI funded two SBIR Phase II contracts (Dynamic Clinical Systems and Caracal, Inc.) to develop a software system to provide integrated, ongoing PRO measurements and timely, efficient,

and individualized information for monitoring patient progress and improving decision making in routine oncology patient care. The long-term goal is to develop computerized PRO data measurement and information systems for use by clinicians and patients that include cancer-specific symptoms and quality-of-life domains, using well-validated instruments or item banks and computer adaptive testing administration to gather patient-reported data for use in clinical practice. Such systems would provide as-needed reports to patients and treating clinicians to assist in informed decision making to improve cancer care.

Cancer Survivorship Research

NCI's Office of Cancer Survivorship (OCS), in partnership with the American Cancer Society and the Lance Armstrong Foundation, held its third biennial cancer survivorship research conference, *Cancer Survivorship: Embracing the Future*, October 4–6, 2006, in Bethesda, Maryland. Key aims of the conference were to: 1) identify future directions of cancer survivorship research, 2) examine advances in e-health and communications, 3) identify challenges to follow-up care for cancer survivors, 4) understand and address the needs of cancer caregivers and families, and 5) review research and strategies to address health disparities in cancer survivorship. Information from this meeting and slide presentations are available on the Web at: http://dccps.nci.nih.gov/ocs/embracing_future/index.html.

NCI devoted an entire edition of the *Cancer Bulletin* to cancer survivorship: http://www.cancer.gov/ncicancerbulletin/NCI_Cancer_Bulletin_101706/page1.

NCI, in collaboration with CancerCare, the Lance Armstrong Foundation, the Intercultural Cancer Council, Living Beyond Breast Cancer, and the National Coalition for Cancer Survivorship presented its fifth annual three-part series of telephone education workshops entitled, "Cancer Survivorship: Living With, Through, and Beyond Cancer." The free series, supported by funds from NCI and the Lance Armstrong Foundation, offers cancer survivors, their families, their friends, and healthcare professionals research-based information about, and tips for coping with, common symptoms and concerns that persist or arise after treatment ends.

- Part I of the 2007 series, held on April 17, focused on "Neuropathy and Joint Aches: New Post-Treatment Challenges."
- Part II, held on May 15 and titled, "My Treatment Is Over: Why Do I Feel So Alone and Sad?" covered the lingering emotional impact of cancer.
- Part III, which will take place on June 19, addresses the topic of "Finding Hope and Meaning After Treatment."
- In the past several years, the programs have had over 1500 participants on any given call. In addition, listeners from over two dozen countries around the world have joined the calls, providing global reach for this information. After airing, all of the programs are saved for podcast in two file formats: RealPlayer and MP3.

For more information about the program go to: <http://dccps.nci.nih.gov/ocs/teleconference5.html>.

NCI's Office of Cancer Survivorship continues to provide an up-to-date portfolio of funded research in cancer survivorship available online at: <http://survivorship.cancer.gov/>.

Complementary & Alternative Medicine (CAM) Research

NCI funds CAM research in palliative care, which is coordinated through NCI's Office of Cancer Complementary and Alternative Medicine (OCCAM). Information for investigators and the CAM portfolio of funded grants are available at the OCCAM Web page: <http://www.cancer.gov/cam>.

Palliative Care and Symptom Management Funding Opportunities

NCI and other NIH Institutes and Centers continue to announce funding opportunities in the broad arena of palliative care from decision-making, biobehavioral, and health disparities research to pain, caregiving, and end-of-life research. Web page is: <http://www.cancer.gov/researchandfunding/announcements/palliativecare>.

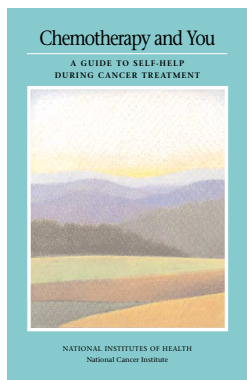
Education

(continued from page 1)

Education for Patients and Caregivers

NCI's Office of Communication and Education is revising a number of NCI's symptom management publications focusing on revised content with improved readability using plain language and updated formatting. The educational materials will eventually be on the NCI's cancer.gov Web site and available for free by ordering online or through the CIS's toll-free number (1-800-4-CANCER). These include:

- **Pain Control - Support for People with Cancer:** This booklet is being updated to include more information on the common misunderstandings and issues patients have regarding pain control, medicines, and side effects, communicating with your health care team about pain, and psychosocial issues that arise with pain. There is a revision of its Spanish counterpart underway as well.
- **Chemotherapy and You and Radiation Therapy and You:** Both are revised to focus more on supportive care and managing the symptoms and side effects of cancer treatment. The booklets are formatted so that each side effect has its own section. Therefore, if the health professional chooses to do so, this format allows for tailoring the information of a patient's side effects by copying select pages of the booklet. Spanish



versions are being created as well.

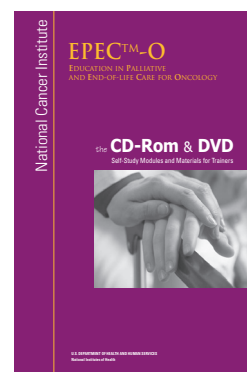
- **What to Do** is a series of fact sheets for managing symptoms of chemotherapy and radiation. These fact sheets were taken from the information presented in the new **Chemotherapy and You** and **Radiation**

Therapy and You booklets and modified for patients with low literacy levels. An accompanying booklet for the health provider on how to use the fact sheets is available with the series.

Facilitating Translation of Palliative Care into Practice

Efforts to broadly disseminate the EPEC™-O (Education in Palliative and End-of-Life Care-Oncology) curriculum for oncology health professionals and to change clinical practice continued last year.

- EPEC™-O on CD-ROM is now available. NCI is partnering with American Society of Clinical Oncology (ASCO), the Hospice and Palliative Nurses Association (HPNA), the Oncology Nursing Society (ONS), and other professional organizations to disseminate the program. The package includes a section of Self-Study Modules, section of Materials for trainers, and DVD of video vignettes. CME and CE credits are being offered by ASCO and HPNA respectively, and the anticipated launch date is June 1. Additional information about the curriculum and ordering instructions can be found at: <http://www.cancer.gov/aboutnci/epeco>.
- A national train-the-trainer seminar of EPEC™-O for the Indian Health System, co-sponsored by the Indian Health Service



(IHS) and NCI, was held in January 2007 at Window Rock, AZ. In addition, a module on Cultural



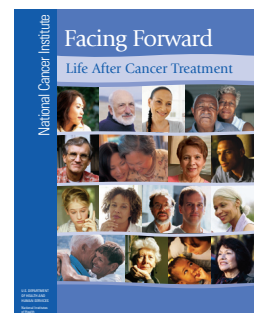
Considerations for American Indian and Alaska Natives was added to the EPEC™-O materials for the seminar, and a culturally representative video vignette to accompany the module was filmed at the seminar. Based on the success of the initial seminar, subsequent regional seminars are currently being planned.

- Building on current collaborative groundwork among IHS, NCI, and other strategic partners, efforts are being initiated to bring together IHS, Tribal Leadership, NCI, and significant external expertise to develop a Comprehensive Strategic Plan to translate palliative care knowledge into practice throughout Indian Health System. The plan would address issues critical to translating research to practice such as enhancing the capacity of care systems, reducing barriers to providing or receiving palliative care, and improving the competency of clinicians in the system to provide palliative and end-of-life care.
- NCI, in partnership with Medscape, sponsored a pilot Web posting of the EPEC™-O module, Last Hours of Living. From September 2006 through March 2007, over 20,000 health care providers (physicians, nurses, nurse practitioners, pharmacists, etc.) completed the activity and applied for continuing education credit through Medscape. Possible further collaboration is being explored.

communication between clinicians and patients. This summary explores important outcomes of communication, factors affecting communication, and communication skills.

- Additional PDQ Supportive Care summaries on palliative care issues patients may face during and after their cancer treatment may be found at: <http://www.cancer.gov/cancertopics/pdq/supportivecare>.
- Results of newsworthy clinical trials in palliative care are highlighted under the section Supportive Care Trial Results, in addition to disease specific progress in the clinical trials portal of cancer.gov at: <http://www.cancer.gov/clinicaltrials/results/supportive-care>.
- The NCI Fact Sheet: *Follow-Up Care After Cancer Treatment: Questions and Answers* was revised this year and also emphasizes identifying and addressing the lingering effects of treatment, as well as screening for, and where possible preventing, adverse late effects. This revised fact sheet is available at: <http://www.cancer.gov/cancertopics/factsheet/Therapy/followup>.

This practical guide is a companion to the [Facing Forward series](#) and helps patients think about and plan for their medical care after treatment ends.



NCI's Web Site: cancer.gov

- The PDQ Supportive Care Editorial Board is finalizing “Last Hours of Life” summary that covers care during the last days to hours of life, including common symptoms, ethical dilemmas, and the role of the oncologist in caring for patients and their families during this time. This summary will be on NCI’s web site by summer 2007.
- Another summary under development is on



Training



The NCI's Cancer Training Branch, which supports the bulk of the NCI's efforts in extramural training and career development, recognizes the

need for individuals trained in palliative care for cancer patients. Several of the funding mechanisms the Branch utilizes in pursuit of its mission to help train the cancer research workforce of the future are currently employed to support training and education in cancer palliative care. Most of these resources are provided through the Cancer Education (R25E) Program. In Fiscal Year 2006 18 R25 Awards were funded at a total cost of approximately \$5.5 million. These Programs target a diverse clinical audience that includes oncologists, primary care and geriatric physicians, nurses, medical students, and individuals working in hospices and nursing homes. The goals of the Programs range from efforts to enhance the dissemination of relevant clinical practice findings to the development of specific curricula to educate clinical audiences.

In addition to these institutional programs, a number of individual Career Development Awards supported young investigators in their efforts to develop careers in cancer palliative care: Five NCI Cancer Prevention, Control, Behavioral, and Population Sciences (K07) Career Development Awards and one NCI Established Investigator Award (K05) in Cancer Prevention, Control, Behavioral and Population Sciences were supported in 2006 at a total cost of about \$1 million.

More information about these and other training and career development mechanisms is available on NCI's Web page for training opportunities: <http://www.cancer.gov/researchandfunding/training>.

NCI's Palliative Care Working Group Division of Cancer Control and Population Sciences (DCCPS)

Neeraj Arora, Patient-Centered Communication Initiative

Arnold L. Potosky, Health Services & Economics Branch, Applied Research Program

Bryce Reeves, Outcomes Research, Applied Research Program

Julia Rowland, Director, Office of Cancer Survivorship

Division of Cancer Prevention (DCP)

Ann O'Mara, Program Director, Symptom Management Portfolio, Community Clinical Oncology Program

Division of Cancer Treatment and Diagnosis (DCTD)

Andrea Denicoff, Nurse Consultant, Palliative Care Initiatives Coordinator, Cancer Therapy Evaluation Program (CTEP)

Ted Trimble, HR-QOL Chair, Surgery Section Chief, Senior Investigator, CTEP

Jeff White, Director, Office of Cancer Complementary and Alternative Medicine

Office of the Director (OD)

Cheryl Arenella, Office of Communications & Education (OCE)

Robin Baldwin, PDQ Supportive Care Board Manager, OCE

Louise Cunningham, Office of Education & Research Dissemination, OCE

Annette Galassi, Cancer Information Service, OCE

Belinda Locke, Minority Training Grants, Office of Centers, Training, and Resources (OCTR)

Rick Manrow, Office of Cancer Information Products & Systems, OCE

John Carl Oberholtzer, Cancer Training Branch, OCTR

Anita Ousley, Professional Education, OCE