

# ELNEC Connections

## End-of-Life Nursing Education Consortium

### Welcome to the Fall 2005 Issue!

The End-of-Life Nursing Education Consortium is pleased to bring you the Fall 2005 issue of *ELNEC Connections*, a quarterly newsletter to showcase efforts in end-of-life nursing education. This newsletter spotlights project developments and provides resources that may be useful to you as an ELNEC trainer. ELNEC is a national education program to improve end-of-life care by nurses, which was originally funded by a major grant from the Robert Wood Johnson Foundation and now has support from the National Cancer Institute, and the Archstone and Aetna Foundations. ELNEC is administered through a partnership between the American Association of Colleges of Nursing (AACN) and the City of Hope National Medical Center (COH).

### Pediatric Nurses Attend Third ELNEC-PPC Course

Pediatric nurses from around the country attended the 3<sup>rd</sup> Annual National ELNEC-PPC Course in Pasadena, CA on August 3-5, partially funded by the Aetna Foundation. Eighty-five pediatric nurses reviewed the ELNEC curriculum, participated in 5 non-drug lab stations (art, play, spiritual, imagery/ relaxation and massage/cold and heat), and exchanged ideas and thoughts at the town hall meeting and roundtable discussions.

A fourth national ELNEC-PPC course will be held in August 2006.



ELNEC-PPC Participants

### Two ELNEC-Core Courses Break Attendance Records for 2005

On October 10-12, 130 nurses from the state of California met at the Pasadena Westin for the ELNEC-Core Training Program which was partially funded by the Archstone Foundation. Nurses came representing acute care facilities, hospices, clinics, long-term facilities, and universities from 52 California cities.

In addition, 145 nurses, representing 29 states, the District of Columbia and Nigeria will attend an ELNEC-Core Training Program in Washington, DC on October 28-30. Nurses from various clinical settings such as oncology, intensive care, emergency room, women's health, and hospice will participate. University nursing faculty will also be attending this non-grant funded course.

Due to the overwhelming interest in both of these ELNEC-Core courses, two additional courses will be held in 2006. See below for further details.



### Seventy-Five Nurses Attend ELNEC-Oncology

The third ELNEC-Oncology Training Program took place in Pasadena, CA on September 14-16. The ELNEC-Oncology program, funded by the National Cancer Institute (NCI), has to date trained 206 Oncology Nursing Society (ONS) members, representing 111 out of 222 ONS chapters. One additional NCI grant-funded oncology course will be offered in September 2006. For more details, see below.

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### Five ELNEC Courses Scheduled for 2006

- February 15-17: ELNEC-Core, Westin Hotel, Pasadena, CA (for CA nurses only)
- April 19-21: ELNEC-Core, Marriott Airport Hotel, Kansas City, MO
- June 21-23: ELNEC-Graduate, Hilton Hotel, Pasadena, CA (for graduate nursing faculty only)
- August 2-4: ELNEC-Pediatric Palliative Care, Disney Paradise Pier Hotel, Anaheim, CA
- September 13-15: ELNEC-Oncology, Hilton Hotel, Pasadena, CA

To obtain a copy of the ELNEC-Oncology application, check with your ONS chapter president. All other applications are on the ELNEC Website: <http://www.aacn.nche.edu/ELNEC/index.htm>.

# ELNEC-Pediatric

**Wendy Mosiman**, [Wendy\\_Mosiman@via-christi.org](mailto:Wendy_Mosiman@via-christi.org)

*Via Christi Regional Medical Center  
Wichita, KS*

In July 2005, 75 nurses, social workers, child life specialists and chaplains attended an ELNEC-PPC Course, sponsored by the Via Christi Foundation and Auxillary. Tracy Carroll, a nurse and the mother of McKenna, a child with trisomy who lived almost 9 months, shared the story of their journey.



**Greg Burns**, [rndirector@jasonprogram.org](mailto:rndirector@jasonprogram.org)

*The Jason Program  
Saco, ME*

In September, Greg was in Bangor Maine, using elements of the ELNEC Pain Management Module for a presentation at The Maine Pain Initiative Symposium.



**Carole Kenner**, [Carole-Kenner@ouhsc.edu](mailto:Carole-Kenner@ouhsc.edu)

*University of Oklahoma  
Oklahoma City, OK*

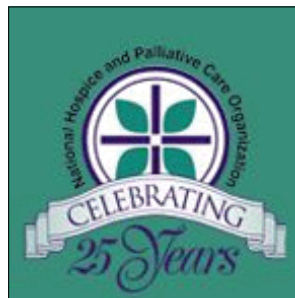
In August and September, Carole presented overviews of ELNEC at the following conferences:

- 5<sup>th</sup> U.S./Russian Nursing Conference sponsored by Providence/Portland Medical Center, Moscow, Russia.
- Neonatal, Flight and Emergency Nurses Conference, Christchurch, New Zealand.



**Betty Davies**, [betty.davies@nursing.ucsf.edu](mailto:betty.davies@nursing.ucsf.edu)

*University of California at San Francisco  
San Francisco, CA*



The annual National Hospice and Palliative Care Organization Clinical Conference and Scientific Symposium will be held in San Diego, CA in April 2006. A special pediatric focus will be part of this conference. Betty is asking for recommendations for presenters (including yourself) or topics.

Please submit your ideas or proposed sessions (60 or 90 minutes long) to Betty.

**Terea Giannetta**, [tgiannetta@childrenscentralcal.org](mailto:tgiannetta@childrenscentralcal.org)

*Children's Hospital Central California  
Madera, CA*

In June, Children's Hospital Central California held the 4<sup>th</sup> Annual Pediatric Palliative Care conference. Terea presented the Communication Module with reference to communication with siblings. This presentation was taped and will be used for an online version of pediatric palliative care for physicians in her community.



**Catherine Klatzker**, [cklatzker@chla.usc.edu](mailto:cklatzker@chla.usc.edu)

*Children's Hospital  
Los Angeles, CA*

Being part of one of only two level I pediatric trauma centers in Los Angeles County, Catherine and other staff members at Children's Hospital of Los Angeles (CHLA) treat the sickest, most seriously injured children. Working with these children and their families can take an emotional, physical and spiritual toll, particularly on the staff in the Pediatric Intensive Care Unit (PICU). There were 82 deaths among the 1,100 severely and terminally ill patients the nurses cared for in the unit last year, and it would be impossible not to be affected by grief and loss. "Eighty-percent of all deaths in pediatric hospitals happen in ICUs," says Catherine, citing national statistics. However, she adds, "many ICU caregivers don't receive the proper training to help prepare them emotionally for such experiences." To help caregivers cope with "compassion fatigue," the PICU Committee on Family Centered Care created a one-day retreat designed to help doctors, nurses and others take care of themselves while caring for their extraordinarily sick patients. Led by a meditation and psychotherapy expert, the retreat offered coping strategies, such as experiential exercises and meditation and relaxation techniques, to deal with end-of-life issues. It gives participants a forum to share their bereavement experiences.

The idea came to Catherine last year after she attended a bereavement workshop for healthcare professionals. Catherine, who chairs the PICU committee, shared what she learned with the group and says, "Everyone agreed we needed to do this here."



# ELNEC-Oncology

**Agnes Wong**, [aggiern1@aol.com](mailto:aggiern1@aol.com)

*San Francisco Bay Area ONS Chapter (SFBAONS)*

Agnes and Michelle Gabriel have written two articles on symptom management for their ONS chapter newsletter. An additional article will be written later this year. They have entitled this series, "Palliative Care Corner." These articles cover common symptoms that cancer patients experience in advanced disease and at end-of-life. Part I covered anorexia/cachexia, constipation, and diarrhea. Part II covered dyspnea and fatigue. Part III will cover anxiety, delirium, agitation, confusion and restlessness.



**Helen James**, [Helen.James@bhs.org](mailto:Helen.James@bhs.org)

*Western Massachusetts ONS Chapter*

Helen has been working with a physician to start a Supportive Care Clinic once a week to follow patients on concurrent radiation and chemotherapy, as well as patients with pain, persistent nausea, cachexia, and other nutritional issues. The clinic offers added patient/family support and interventions to situations that are very stressful and require close monitoring.

**Carma Erickson-Hurt**, [CJErickson@nmcsd.med.navy.mil](mailto:CJErickson@nmcsd.med.navy.mil)

*San Diego ONS Chapter*

The Southern California Cancer Pain Initiative (SCCPI) has recently announced that Carma will be one of this year's award winners. In October, 2005, Carma will be honored, with other interdisciplinary team members across Southern California for outstanding work in assessing and managing cancer pain and participating in other pain initiatives. Carma will be particularly highlighted because of her exceptional work last year in Indonesia working with those affected by the tsunami. In 2004, Marlon Saria, Carma's ONS chapter colleague who attended the first ELNEC-Oncology course, was also a SCCPI award winner.

In addition to Carma's many activities, she recently taught an ELNEC course to 45 Navy nurses and hospital corpsmen. In this class were four military nurses from the Zambian Defense Force. Having recently implemented a palliative care program, the Zambian nurses reported that the ELNEC course has empowered them to go back home and talk with their patients about death and dying.



Carma with some Indonesian nurses.

## International Outreach

Are you currently involved in presenting or negotiating presenting ELNEC internationally? The ELNEC Project Office receives many inquiries about international efforts to take ELNEC to different parts of the world. A comprehensive list of international opportunities is currently being compiled. If you have contacts from different countries who have either received ELNEC training and/or who might be interested in receiving training, please notify us at [pmalloy@aacn.nche.edu](mailto:pmalloy@aacn.nche.edu).

An excellent example of an ELNEC trainer who has worked to bring ELNEC to an international audience is Carole Kenner (see page 2 for Carole's most recent travels).

Carole is currently working with the Russian Nurses Association and a neonatal nurse to seek funding for the translation



and adaptation of ELNEC into Russian. "There continues to be a great need and interest globally for end-of-life and palliative care. In Russia, for example, hospice nurses and general medical/surgical nurses feel that they need more information about actual care."

Physicians also feel they are inadequately trained and ill-prepared to work with dying patients and their families," states Carole. New Zealand nurses have also expressed the need for increasing awareness about palliative care. Pain management continues to be a global issue.

If you have any contacts in Russia and/or New Zealand, please contact Carole at [Carole-Kenner@ouhsc.edu](mailto:Carole-Kenner@ouhsc.edu)



**Don't forget - if you change your e-mail address, notify the ELNEC Project Office so we can keep you updated on the latest ELNEC news.**  
[nbrown@aacn.nche.edu](mailto:nbrown@aacn.nche.edu)

**For a complete list of upcoming trainings and course descriptions, check the ELNEC Web site at:**  
[www.aacn.nche.edu/ELNEC](http://www.aacn.nche.edu/ELNEC)



# ELNEC Trainer Roundup

Here is a synopsis of what some trainers have been doing since their ELNEC participation. **Please send updates on your ELNEC activities, including pictures of your training activities, to the Project Office at [pmalloy@aacn.nche.edu](mailto:pmalloy@aacn.nche.edu) by December 10, 2005 for the Winter issue.**

**Jeanne Weggel, [jweggel@shcc.hshs.org](mailto:jweggel@shcc.hshs.org)**

*Sacred Heart Hospital  
Eau Claire, WI*

Jeanne works in the Palliative Care Service which is a consult service, heavily used by the interdisciplinary team to provide care to patients throughout the entire hospital who face a wide range of end-of-life issues. Jeanne collaborated with the marriage and family therapist, who is a member of the team, to write pamphlets dealing with nine different ethical decisions related to the end of life to give to patients and family members at times when the service is not available. They are easy to read and include stories which help illustrate the issues discussed. The interdisciplinary team, as well as patients and their families, have found them helpful.



The pamphlets cover the following issues: Palliative Care Service, Hospice Care, Advance Directives: Power of Attorney for Health Care, The Dying Process: Comfort Care, Withdrawal of Ventilator to Allow Natural Death, Stopping Dialysis to Allow Natural Death, Artificial Nutrition and Hydration, Cardio-Pulmonary Resuscitation, and Medical Dilemmas and Moral Decision Making.

**Bonnie Walsh, [bwalsh@hospiceofrockland.org](mailto:bwalsh@hospiceofrockland.org)**

*Hospice of Rockland  
New York City, NY*

In June 2005, Bonnie presented an ELNEC course to 25 nurses and used film clips, for the first time, to enhance the learning process and found that it was very well received. A ten-minute clip from the movie "Philadelphia" was used to sensitize the nurses to "being with" a patient and listening. The last ten minutes of the film "In America" was used in the Grief, Loss and Bereavement Module.

**Barbara Bailey, [bbailey@SDHospice.org](mailto:bbailey@SDHospice.org)**

*San Diego Hospice and Palliative Care (SDHPC)  
San Diego, CA*

SDHPC continues to offer an annual conference on End-of-Life Care jointly with Point Loma Nazarene University Department of Nursing. 2006 will mark the fourth year that the two-day conference will be offered. ELNEC is the basis of the content that is presented. Barbara and her colleague, Lois Wagner, are the course coordinators.



**Janet Alexander, [jgalexan@samford.edu](mailto:jgalexan@samford.edu)**

*Ida V. Moffett School of Nursing, Samford University  
Birmingham, AL*

Janet will be directing a \$46,700 grant from the 3M Company that will enable nursing students to study end-of-life care. The 3-year program entitled, "Colleagues in Compassionate Care: A Volunteer Learning Program between Samford University and New Beacon Hospice," will allow nursing students to volunteer in order to provide relief to patients and caregivers at New Beacon Hospice. This program will enrich the undergraduate curriculum by combining theory and practice experiences related to end-of-life care and will broaden both student and faculty understanding of the importance of volunteerism.

**Marjorie Schaffer, [m-schaffer@bethel.edu](mailto:m-schaffer@bethel.edu)**

*Bethel University  
St. Paul, MN*

From February to May 2005, Marjorie was in Norway on a Fulbright Research/Lecture Award. While in Norway, she presented "Nursing Care at the End of Life" to master's students at the University of Oslo. Her research project focused on "Norwegian Perspectives on End-of-Life Decision-Making for Elders and Families." She interviewed health professionals in nursing homes, hospices, home care, and hospitals. Marjorie also interviewed some elders and family members about end-of-life decision-making. She is currently working on several articles about the research results for publication. On October 22, Marjorie will be presenting "Quality of Life at the End of Life" at the Minnesota Nurses Association Centennial and Annual Convention. Marjorie states, "The ELNEC Curriculum was integral to my preparation for all these activities."

**Beth Traudes, [TraudesB@missouri.edu](mailto:TraudesB@missouri.edu)**

*University of Missouri  
Columbia, MO*

Beth attended the very first ELNEC course and has been teaching the ELNEC curriculum to approximately 60 students per semester since 2001. She also serves on the University Hospital's Palliative Care Committee



and is a member of the Missouri End-of-Life Coalition. In September, the coalition held a local town hall meeting at the public library, hoping to reach more people in the community about the need for an advanced directive.

# ELNEC Trainer Roundup

## ELNEC Trainer Linda O'Brien Works to Resolve Ethical Dilemmas in Long-Term Care Settings

Linda O'Brien has long been committed to educating healthcare professionals about the resolution of ethical dilemmas arising in long-term care settings. As project director and co-investigator of the New Jersey Stein Ethics Education and Development Project (NJ SEED), Linda worked with others in providing training for NJ long-term care regional ethics committees to facilitate sound medical decision-making with the ultimate goal of improving the quality of care provided to long-term residents in the state. Funded by the Louis and Bessie Stein Foundation and the Robert Wood Johnson Foundation-New Jersey Health Initiatives program, the NJ SEED project has provided families and institutional staff members access to skilled mechanisms that can assist in resolving ethical dilemmas, and creating a moral environment in the long-term care community. The evaluation and final project report for the NJ SEED effort, supported by a grant from the Commonwealth Fund, provided strong evidence that effective and pragmatic clinical ethics education for nursing home professionals, together with support from both on-site and regional ethics committees, significantly aids long-term care facilities in both analyzing and resolving complex ethical dilemmas within the clinical setting.



In 2002, Linda founded Elder Care Ethics Associates (ECEA), a non-profit corporation that provides clinical ethics education to long-term care providers, assists them in quality improvement initiatives, and facilitates access to national resources, research, program support and membership in the ECEA Pain Management Network. This corporation grew out of her leadership of the NJ SEED Project. To date, Linda and her staff have worked with several facilities in Wyoming and have made preliminary arrangements to provide training in Georgia, Florida and California.

A series of high quality nursing home specific train-the-trainer educational modules on topics including best practices in palliative care for certified nursing assistants and comprehensive pain management program in the nursing home setting for staff professionals is available for purchase. If you would be interested in discussing how you might partner in bringing similar ethics training and service initiatives to your

geographic region, contact Linda directly at 856-234-7233 or [Eldercare02@aol.com](mailto:Eldercare02@aol.com) To view available educational modules see: [www.eldercareethicsassociates.com/](http://www.eldercareethicsassociates.com/).

## Textbook of Palliative Nursing Second Edition

(Release date October 14, 2005)

Edited by **Betty R. Ferrell**, Research Scientist, Department of Nursing Research and Education, City of Hope National Medical Center, and **Nessa N. Coyle**, Director, Supportive Care Program, Pain & Palliative Service, Department of Neurology, Memorial Sloan-Kettering Cancer Center

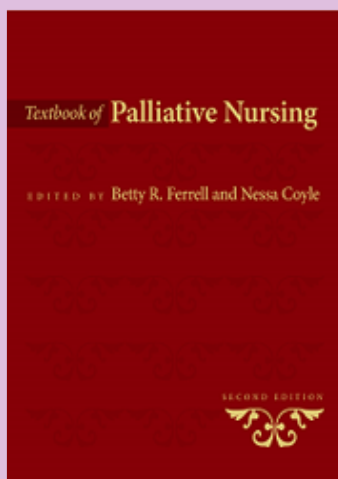
### Reviews from the previous edition:

"...an outstanding achievement! This book is the first comprehensive treatise on the art and science of palliative care nursing."

—*Journal of Pain and Symptom Management*

"...the editing is so well done that the chapter-to-chapter segues are seamless."

—*Respiratory Care*



To purchase a copy of the book at a 15% discount, please see [www.aacn.nche.edu/ELNEC](http://www.aacn.nche.edu/ELNEC).

All royalties will go to the Hospice and Palliative Nurses Association (HPNA).

# Inspiration, News & Resources

## ELNEC Trainer Works With Students to Produce EOL Documentary

Linda Strodman, assistant professor of nursing at the University of Michigan, is the project director for a new documentary and instructor's guidebook dealing with end-of-life issues. She has worked closely with interdisciplinary health professional students to produce this film. In today's highly technological health care system, there are times when the trajectory of life-threatening illness shifts from a curative to comfort focus as the patient faces death. This shift is often the hardest decision-making process that health professionals face in their interactions with patients and families.

"Evan Mayday's Good Death," illustrates how one team and one family confronted these painful and difficult issues head-on and how they all had to work together to rise above their own issues, concerns, and fears so they could collectively grant a dying patient's last request. Using a real patient scenario of a 63-year-old man who chooses to have life-support withdrawn, health professionals and students learn about collaborative care and the creativity that evolves in providing an individualized and personal death experience with recognition not only of the suffering and struggles of the patient and family, but also those that the health professionals themselves face in caring for dying patients.

To order this film and instructor's guidebook, contact Linda at 734-647-0189 or [Strodma@umich.edu](mailto:Strodma@umich.edu). A second film, in the editing stage, addresses palliative care issues for children and their families.

## ELNEC-PPC Goes Online: International Outreach Program at St. Jude Children's Research Hospital Provides This Service

The ELNEC Pediatric Palliative Care Course (ELNEC-PPC) is now available on Cure4Kids! This online presentation was a collaborative effort among Cure4kids of the International Outreach Program of St. Jude Children's Research Hospital, the City of Hope Medical Center and the American Association of Colleges of Nursing. This course, which has been accessed 2,627 times since May 22, 2005, was developed for health care professionals to provide a more thorough understanding of how the end of a child's life impacts families, friends, and care givers. The majority of those who have accessed the site are from low resource countries. Cure4Kids is a professional medical education Web site developed by the Cure4Kids team from the International Outreach Program at St. Jude Children's Research Hospital. Cure4Kids has hundreds of online seminars and conferences, a digital library, and group collaboration workspaces. Cure4Kids is available to any health care professional or research staff at no charge. New users can register at [www.Cure4Kids.org/register](http://www.Cure4Kids.org/register) ELNEC trainers are invited to view this site, at no cost, by going to the public Web link at: [www.cure4kids.org/ums/home/public\\_area/c4k\\_seminar\\_list.php](http://www.cure4kids.org/ums/home/public_area/c4k_seminar_list.php).



## New MSN Program with Concentration in Palliative Care Being Offered

The University of Illinois at Chicago, College of Nursing has just begun a new certificate program in palliative care for nurses and other allied health professionals serving a population that needs palliative care and end-of-life situations. For more information, contact P. Melissa Hernandez at [pmhern@uic.edu](mailto:pmhern@uic.edu)

## Healthcare Professionals on the Front Lines of Caring for Those Affected by the Hurricanes

Everyday, nurses care for and assist people who are coping with an illness, injury or tragedy. In the wake of the devastating hurricanes that have hit the southern coast of the United States over the past few weeks, the Center to Advance Palliative Care (CAPC) is offering tips from "Disaster: Coping with Tragedy" to assist healthcare providers in supporting people directly involved in these catastrophes. For more information, go to [www.capc.org](http://www.capc.org)



## ELNEC Fact Sheet Updated

Did you know that currently 2,180 nurses have completed national ELNEC train-the-trainer courses? For an update on ELNEC facts, go to: [www.aacn.nche.edu/ELNEC/about.htm](http://www.aacn.nche.edu/ELNEC/about.htm).



## Need a List of Videos for Your Next ELNEC Course?

There is currently a list of over 250 videos that are on the City of Hope/Palliative Care Resource Center website that are ideal for use during an ELNEC training program. To access this list, go to <http://prc.coh.org> and click on "End of Life/Palliative Care." Scroll down to "C. Educational Materials/Curriculum" and click on #2: "Care of the Dying Patient - Video Listing"



## Need a Palliative Care Financial Tutorial?

Download a comprehensive palliative care financial tutorial at the Center to Advance Palliative Care Web site, [www.capc.org](http://www.capc.org). This free tutorial reviews how to estimate program volume and financial impact and includes draft budget forms.