

ELNEC Summer 2007 Connections

End-of-Life Nursing Education Consortium

Welcome to the Summer 2007 Issue!

The End-of-Life Nursing Education Consortium is pleased to bring you the summer 2007 issue of ELNEC Connections, a quarterly newsletter to showcase efforts in end-of-life nursing education and practice. 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. The project, which began in February 2000, was funded by a major grant from The Robert Wood Johnson Foundation. Additional funding has been received from the National Cancer Institute, and Aetna, Archstone, and California Healthcare 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).

ELNEC-Super Core to Debut in October



Due to the high demand for ELNEC-Core, ELNEC-Graduate, and ELNEC-Oncology, an ELNEC-Super Core curriculum is being developed. The ELNEC-Core syllabus, the original curriculum, was developed for undergraduate nursing faculty, continuing education providers, staff development educators, and staff nurses. Using the ELNEC-Core curriculum as a foundation, both ELNEC-Graduate and ELNEC-Oncology were developed to meet the unique needs of graduate nursing faculty and oncology nurses, respectively. Because the content and PowerPoint slides are very similar, these three courses will be merged into one curriculum titled “ELNEC Super-Core.” When attending an ELNEC Super-Core course, the ELNEC-Core course will be presented. Multiple case studies will be provided to meet the broad needs of the three curriculums. During a national ELNEC Super-Core train-the-training session, there will be separate break-out times for case study review and progressive role play, depending on which curriculum you will need. Nurses, as well as other members of the interdisciplinary team, are invited to attend the October course. To register, download the application at www.aacn.nche.edu/ELNEC and click on “Courses for 2007.”

Four ELNEC Training Programs Remain for 2007

- August 1-3: ELNEC-Pediatric Palliative Care, Anaheim, CA
- September 12-14: ELNEC-Geriatric, Pasadena, CA
- October 17-19: ELNEC-Super Core, Washington, DC
- November 7-9: ELNEC-Critical Care, Pasadena, CA

Please forward these dates to any of your colleagues who need to update their knowledge in end-of-life/palliative care. To obtain further information about these courses and/or to register, go to: www.aacn.nche.edu/ELNEC.

Confirmed 2008 Schedule

- February 6-8: ELNEC-Super Core, Pasadena, CA
- February 20-21: ELNEC-Super Core (emphasis on Graduate faculty), Newport Beach, CA (pre-conference to AACN Master’s Conference)
- June 25-27: ELNEC-Super Core, Chicago, IL
- July 9-11: ELNEC-Pediatric Palliative Care, Pasadena, CA

Note: Dates for Critical Care and Geriatric courses pending. Check ELNEC website for updates.

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TWO ELNEC Courses Held in Washington, DC This Spring: *ELNEC-Pediatric Palliative Care and ELNEC-Critical Care Offered*



On March 29-31, 2007, pediatric nurses from around the US attended the fifth national ELNEC-Pediatric Palliative Care (PPC) training program at the Marriott Washington-Dulles Airport Hotel. These trainers represented staff nurses, nurse practitioners, nursing educators, and social workers. To date, 460 pediatric nurses have been ELNEC-PPC trained. On April 2-4, 2007, 90 nurses who work in intensive care, coronary care, burn units, and emergency departments attended the ELNEC-Critical Care (CC) train-the-trainer program. All totaled, 250 critical care nurses have attended one of the three national ELNEC-CC courses since its debut in November 2006.

ELNEC-Core Training Provided in Hawaii



Last spring, the ELNEC Project was invited by the Queen's Medical Center in Honolulu, HI to provide ELNEC training on the Hawaiian island of Oahu. On May 22-24, 67 nurses representing Japan, Guam, 5 of the Hawaiian islands, and the US mainland attended this extraordinary course. Reviewing case studies in small groups and participating in the role plays provided a unique opportunity to learn and experience various cultures. Appreciation goes to both Queen's Medical Center and Kokua Mau for their support of this training.

Seven Japanese nurses attended the ELNEC training in Hawaii.
Front Row L to R: Noriko Iba, Keiko Tamura, Sayaka Sakamoto
Back Row L to R: Naoko Hayashi, Tomoko Izawa, Sayuri Kitamaya, Mariko Irie

ELNEC-ONCOLOGY

Four ELNEC-Oncology Trainers Given Award at ONS Congress

On Monday, April 23, 2007 at the Mandalay Bay Convention Center in Las Vegas, NV, four ELNEC-Oncology trainers were given awards for the outstanding way they have implemented and disseminated the ELNEC-Oncology curriculum in their ONS chapter and institution. These award winners attended the September 2005 training program. They are:

- **Linda Horn-Thompson:** Baton Rouge Oncology Nurses Chapter, LA
- **Peter Miller:** North Valley ONS Chapter, CA
- **Lori Molzer and Sara Yokel:** Southeast Nebraska ONS Chapter, NE

To read more about these award winners, go to: <http://www.aacn.nche.edu/ELNEC/Oncology.htm>.

ATTENTION ELNEC-ONCOLOGY NURSES: Your colleagues are invited to attend the first ELNEC-Super Core train-the-trainer program October 17-19, 2007 at the Marriott Washington-Dulles Airport Hotel (Washington, DC area). For more information and/or to register, go to: www.aacn.nche.edu/ELNEC.

TRAINER ROUND-UP: ELNEC-CORE

CNO Mandates That All Nurses Complete ELNEC Training

At Our Lady of Bellefonte Hospital in Ashland, KY, the CNO has made the commitment that all nurses who work there must be ELNEC trained. To accomplish this, ELNEC trainer, Judy Conn, BSN, RN, Palliative Care Coordinator, has divided the ELNEC-Core curriculum into 4 hour classes, held once a month (on the third Thursday of each month). To complete ELNEC training, each nurse must attend all three 4-hour classes. Judy will continue to provide these classes until the aim of having every nurse ELNEC trained is accomplished. If you would like to contact Judy about how she worked with the CNO and other leaders in her institution to implement this goal, you may reach her at JConn@olbh.com.

National Black Nurses Association (NBNA) Holds Regional ELNEC Training:

Sponsored by VITAS and Prairie View A & M



For the first time in its history, the NBNA hosted an entire conference dedicated to end-of-life care. Over 45 nurses completed the regional ELNEC training in Houston, TX and 21 of the 45 participants attended an additional day to complete the train-the-trainer course. ELNEC trainer Pat Tadel was the lead faculty member. For more information on this course, contact Diane Deese, Director of Community Affairs at VITAS Innovative Hospice Care, dd@tmail.com.

ATTENTION ALL ELNEC TRAINERS: *Your colleagues are invited to attend the first ELNEC-Super Core train-the-trainer program October 17-19, 2007 at the Marriott Washington-Dulles Airport Hotel (Washington, DC area). For more information and/or to register, go to: www.aacn.nche.edu/ELNEC.*

ELNEC-PEDIATRIC PALLIATIVE CARE

Hollye Harrington Jacobs Joins ELNEC Project

The ELNEC Project office is delighted to announce that Hollye Harrington Jacobs, MS, RN, MSW has joined the ELNEC team as coordinator of the ELNEC-Pediatric Palliative Care (ELNEC-PPC) training program. In addition, Hollye will assist with the revision of a version of the ELNEC-Core curriculum for use in translation for international courses. Hollye has been involved with the ELNEC-PPC project since its inception in 2002. Hollye was a major consultant on the development of the ELNEC-PPC curriculum. In addition, she has served as faculty. Hollye's expertise lies in pediatric palliative care ethics and child development. If you have specific questions about the ELNEC-PPC training program or international ways of disseminating the ELNEC curriculum, contact Hollye at hollyejacobs@mac.com.

Children's Hospital of WI Develops a Pet Visitation Program



ELNEC-PPC trainer, Beth Kastner, RN, MDiv, CHPN, Palliative Care Clinician at the Jane B. Pettit Pain and Palliative Care Center in Milwaukee, WI, has reported that they now have a pet visitation program. Children may have visits from their domesticated dogs, cats, gerbils, rabbits, and guinea pigs. This program is specifically for a child who is terminally ill, who has an anticipated length of hospitalization to exceed one month, and/or significant signs of regression/depression. If you are interested in reviewing the Infection Control Policy and Procedure regarding Pet Visiting, contact Beth at BKastner@chw.org.

ATTENTION ELNEC-PEDIATRIC NURSES: *Your colleagues are invited to attend the ELNEC-Pediatric Palliative Care Train-the-Trainer program, August 1-3, 2007 in Anaheim, CA. For more information on this course and/or to register, go to: www.aacn.nche.edu/ELNEC.*

ELNEC-GRADUATE

**“Evan Mayday’s Good Death” Film Ready for Purchase:
Film has been shown at all ELNEC-Critical Care Courses with much acclaim**



Dr. Linda Strodman

Since late 2002, Professor Linda Strodman, PhD, RN has been working with Maureen M. Goode Giacomazza, MA, RN, Clinical Nurse Specialist with the Pediatric Palliative Care Consultation Service and nurse ethicist on a Palliative Care Nurse Education Project at University of Michigan Health System in addressing palliative and end-of-life care issues. They have a funded Center on Research in Learning and Teaching Grant for producing two videotapes about providing a "Good Death" from an interdisciplinary care team perspective. Both are engaged in research directed toward improving quality of end-of-life care. They are conducting a research study "Family Satisfaction with End of Life Care" in which families of patients who have died in intensive care units settings are surveyed about their experience. "Currently in the U.S., satisfaction data about quality of care during hospitalization is almost always ascertained only from patients who are discharged alive and families who have lost their loved one are not included," stated Linda.

Evan Mayday was an active, athletic man who had served in the Navy. He owned his own business and loved the outdoors. When the Brighton, Mich. man broke his neck in a diving accident and became a quadriplegic, he became a daredevil in his electric wheelchair, racing his grandkids up and down the driveway. He made it clear he wanted no part of life support or living in a nursing home, and when his health deteriorated enough to make that seem inevitable, Mayday said he was done.

"Evan Mayday's Good Death," a short educational film, produced by Linda and Maureen, chronicles how doctors, nurses, social workers, chaplains and other health care providers worked with Mayday and his wife, Cheryl, to be sure he was making a reasonable decision, and ultimately, to support his choice to remove his ventilator. "It is not the first video on end-of-life health care, but they say it is unusual because it is a case study modeling best practice rather than worst-case scenario. Death is prevalent in our society—it's in our movies, our video games, our life with war and terror from around the world—but it's not something we're preparing doctors and nurses to talk about," said Linda. "We're all going to die, but it's seen as a failure to have a patient do the most natural thing that could happen. As a result, patients are dying in hospital intensive care units when most everyone would rather die in their own homes, and people are dying in moderate to severe pain when it could be controlled. People's lives are being extended by technology, and sometimes beyond when they would want to live," said Maureen.

With funding from the University of Michigan Center for Research on Learning and Teaching, and several other foundation and private donations, Linda and Maureen began work on two videos—one about an adult end-of-life case, and a second on care of children with life-threatening condition. They did not script Mayday's caregivers or his wife. Instead, they just turned the cameras on each person and asked for the story of caring for a 63-year-old man who no longer wanted artificial life support. That led to 10 hours of video, which they pared down to 29 minutes.

Both Linda and Maureen emphasize that the discussions held after viewing the video are as important as the story. The video intentionally raises more questions than it answers, and to the 1,200 or more viewers that have seen the film, they have always asked tough questions about how viewers feel and what they might have done differently. The nurse producers are writing a discussion guide to the Mayday video, to help others who might want to present the video and lead a conversation about its key points. They hope to finish the guides this fall. If you are interested in purchasing this film, check-out the website: <http://www.med.umich.edu/nursing/EndOfLife/mayday.htm>. Linda may be contacted at strodma@umich.edu.

ELNEC-Graduate Award Winner Writes Article



Marjorie Schaffer, PhD, RN, Professor of Nursing at Bethel University in St. Paul, MN has recently had a paper published titled “Ethical problems in end-of-life decisions for elderly Norwegians.” This article was published in *Nursing Ethics*, 14(2), 242-257. <http://dx.doi.org/10.1177/09697330070703707>

Marjorie attended the very first ELNEC-Graduate training program, funded by the National Cancer Institute in June 2003. She was also among the first ELNEC-Graduate award winners. From February-May 2005, Marjorie was in Norway, where she was awarded a Fulbright Scholarship. The award allowed her to do further research on end-of-life decision-making, especially for those living in Norway. You may contact Marjorie at m-schaffer@bethel.edu.

ATTENTION ELNEC-GRADUATE NURSING FACULTY: Your colleagues are invited to attend the first ELNEC-Super Core train-the-trainer program October 17-19, 2007 at the Marriott Washington-Dulles Airport Hotel (Washington, DC area). For more information and/or to register, go to: www.aacn.nche.edu/ELNEC.

ELNEC-CRITICAL CARE

ELNEC-Critical Care Trainer Has Developed Two Tools

Molly Archer, BSN, RN from the Portland VA Medical Center, Portland, OR has written guidelines on how to organize an interdisciplinary meeting. In addition, she has also developed a bereavement informational folder for family members whose loved ones are in a critical care setting. Though Molly authored these two tools, she also had input from multiple services within the VA. If you are interested in reviewing these tools, contact Molly.Archer@va.gov.



Two Trainers Receive Awards for Work With Heart Failure Patients



ELNEC trainers Eileen Mann and Lisa Preston are currently examining the ELNEC curriculum with the intention of adding symptom management of heart failure to the primarily oncology-focused education. Their goal is to disseminate the ELNEC curriculum in

order to increase the awareness and understanding of palliative care and its relation to heart failure. *Palliative Practices in Heart Failure Nursing* is a monthly forum Eileen and Lisa have initiated that is designed to promote an exchange of ideas and clinical experiences, discuss barriers to care, and offer educational opportunities to their colleagues. Guided by the principle of “how can we make your life better,” they encourage collaboration within the patient care team as a means to promote best practice and to provide specialized care to heart failure patients and their families. “At Brigham & Woman’s Hospital (BWH), we are encouraged to create within an academic environment, and are supported in developing innovative, nurse-directed projects that preserve patient and family focused care,” stated Eileen. Their work has recently been recognized by BWH with the honor of the Dennis Thompson Compassionate Care Scholar Award and the Mary Fay Nursing Enrichment Award. These awards provide opportunities for staff to further develop new avenues for health care providers to improve the quality of care for patients and their families. If you would like to learn more about Eileen and Lisa’s work, you may contact them at: embnm@comcast.net.

ATTENTION ELNEC-CRITICAL CARE TRAINERS: Your colleagues are invited to attend the fourth national ELNEC-Critical Care train-the-trainer program November 7-9, 2007 at the Westin Hotel in Pasadena, CA. For more information and/or to register, go to: www.aacn.nche.edu/ELNEC.

ELNEC-GERIATRIC

First Cohort of ELNEC-Geriatric Trainers Report Efforts to Educate Staff

The first national ELNEC-Geriatric train-the-trainer course took place February 1-2, 2007 in Long Beach, CA with 82 California nurses in attendance. These nurses came from skilled nursing and/or long-term care facilities, as well as from hospices who service both types of care settings. These participants have been asked to update the ELNEC Project Office 1, 4, and 12 months post-course. The responses from the participants have been most encouraging. For example:

- Ninety per cent (90%) had spoken to their administration about their ELNEC training.
- Dorothy Bruining, BSN, RN, PHN, NHA from the Artesia Christian Home in Lakewood, CA has completed module 1 and one-half of module 2 with licensed staff. She has also reviewed module 1 with the certified nursing assistants, housekeeping, and maintenance staff. In addition, she has made a presentation about her experience at ELNEC-Geriatric to the facilities' board of directors. dorothyb@achome.org.
- Suzanne Cikowski, BSN, RN and Maris Gordon from Hospice Partners of the Central Coast in San Luis Obispo, CA taught a class at a local community college on pain, non-pain symptoms, and care at the end of life. These same lectures have been used to teach their licensed and unlicensed staff at Hospice Partners. scikowski@sbcglobal.net
- Donna Lockhart, GNP, RN and Sally Erwin, FNP, RN from Kaiser—Continuity of Care/Skilled Nursing Facilities' Department in Santa Rosa, CA are in the process of negotiating with two Kaiser SNF's to have end of life/palliative care beds available. They are using the ELNEC-Geriatric curriculum to present to the staff at the two facilities. donnaklockhart@comcast.net and ervinsal@comcast.net

ATTENTION ELNEC-GERIATRIC TRAINERS: Your colleagues are invited to attend the second national ELNEC-Geriatric train-the-trainer program September 12-14, 2007 at the Westin Hotel in Pasadena, CA. For more information and/or to register, go to: www.aacn.nche.edu/ELNEC.

INTERNATIONAL EFFORTS

Requests for International ELNEC Training Continue: *Various Activities of Promoting Education Provided*

In the past two months, ELNEC trainer, Rodger Strong from San Diego Hospice, has made two trips to various parts of the world to train others in excellent end-of-life care, using the ELNEC curriculum. Rodger has been in Guadalajara, Mexico and in Shanghai, China educating nurses and other healthcare providers about not only the importance of this care, but how to do it well.

ELNEC trainer Sayaka Sakamoto, from Kita-Ku Osaka, Japan, has been working for the past 14 months on translating the ELNEC-Core curriculum into Japanese. Though Sayaka was originally ELNEC-trained in October 2005, she decided to attend the ELNEC course held last month in Hawaii again. This allowed her to hear the lectures again, to meet other Japanese nurses and to enlist their assistance in reading through her translation. "Making the Japanese-version of ELNEC culturally relevant is the most challenging part of translating," stated Sayaka.

ELNEC faculty will be traveling internationally this summer to provide training:

- In July, Nessa Coyle, Patrick Coyne, Betty Ferrell, and Judy Paice will travel to Tanzania to provide ELNEC training to nurses and physicians in both city and rural areas. This trip is being supported by the Oncology Nursing Foundation. In addition, these four attended the International Association of Hospice and Palliative Care (IAHPC) Congress in Budapest, Hungary, where they presented a paper on the international efforts of providing ELNEC education.
- In July, Pam Malloy and Rose Virani will attend Sigma Theta Tau's 18th International Nursing Research Congress in Vienna, Austria and present a paper on the international efforts of disseminating and implementing ELNEC. In addition, Pam and Rose will be hosting a reception for those attendees who are currently promoting excellent palliative care or for those interested in how to get started in providing palliative care in their country. This event will be sponsored by the Open Society Institute.

Be sure to notify the ELNEC project office if you are going overseas to provide ELNEC training. To read what other ELNEC trainers have done internationally, go to: <http://www.aacn.nche.edu/ELNEC/Global.htm>. If you have provided any end-of-life/palliative care education internationally and your name is not on the above-mentioned site, please contact Pam Malloy at pmalloy@aacn.nche.edu.

MESSAGE FROM THE ELNEC PROJECT OFFICE

It is always wonderful to hear from ELNEC trainers. Many e-mail or call me to say that they have just completed a course and that they are so excited that they have had the opportunity to train their colleagues. Sometimes I hear from ELNEC trainers who are frustrated with “the system” and uncertain what to do next. Whatever the e-mail or the phone call is about, it is always a privilege to support ELNEC trainers.

Below is a list of the most “Frequently Asked Questions (FAQ)” that we receive:

Q: It is difficult and challenging to take staff off the units to provide 2-3 days of ELNEC training. Are there other ways to accomplish this training?

A: Yes. Many trainers report that they provide ELNEC training for 1 hour per month (during lunch or after work). For example, the first Tuesday or every month is set aside for ELNEC training. The trainer will present one module and another the next month. These trainings go on continuously, so that if you miss one month, you can pick that module up 9 months later.

Q: After attending the ELNEC training program, I knew there were many things that needed to be changed in my facility to improve the care of those experiencing end-of-life issues. How do I get started in making some of those changes?

A: After attending ELNEC, trainers have stated they are excited and motivated to go back and change systems so that care can be improved in their facility. However, many times there are major barriers that make those changes difficult, if not impossible. Some suggestions:

- Any time you want to make a change, you must have a “**team.**” We accomplish very little alone. You are encouraged to find others in your facility who have the same passion about changing the way dying patients and their families are cared for. When going to the leadership to talk about opportunities for change, you have a better chance of being heard if you have other members of the interdisciplinary team accompany you and supporting the message.
- Make your conversation about improving care for the **PATIENT** and his/her family. Conversations should always be patient-centered and not about you and what you want.
- Use **current data** when talking to the leadership. They love numbers—that’s how they work. For example, if you want to talk about improving pain management in your institution, show them a report loaded with data from the past month. Example: On the medical/surgical unit last month, 72 patients were on PCA’s. Their average pain scores were 8.4. This data shows that we are not properly assessing and managing our patient’s pain.
- Check-out the various **regulatory organizations** (i.e. JCAHO) and use their accreditation recommendations.
- Lastly, appeal to the idea that it is “**the right and ethical thing to do.**”

Q: I attended an ELNEC course in 2003. Do I need to get an updated version of ELNEC?

A: All ELNEC curriculums are updated annually. If you are an ELNEC trainer, you may purchase an updated ELNEC-CD for \$100 by contacting Celeste Jauregui at City of Hope at: cjauregui@coh.org.

Q: I am an ELNEC-Graduate trainer. I would like to purchase the ELNEC-Critical Care and ELNEC-Geriatric CD. May I do that?

A: At this time, the ELNEC-Critical Care and ELNEC-Geriatric CDs are not for sale. The reason for this, is that we are making edits after each course. Both courses are relatively new (have provided three ELNEC-Critical Care courses and one ELNEC-Geriatric course). In addition, we believe that it is important for people to attend the in-person training, if at all possible. Evaluations show that attending a face-to-face training program is valuable in many ways, as it provides opportunities to network with other nurses in the specialty.

MESSAGE FROM THE ELNEC PROJECT OFFICE

Q: How do I maintain my ELNEC certification?

R: A: ELNEC trainers are not certified. The ELNEC course is not a certification course. After completing an ELNEC course you are not certified in palliative care, hospice care, etc. ELNEC is a train-the-trainer and training course. If you are interested in obtaining certification in palliative care, you are encouraged to check-out the Hospice and Palliative Nurses Association at www.hpna.org for further information.

Q: We are just beginning a palliative care service here at our hospital and would like to attend a national ELNEC course. Can people from the interdisciplinary team, other than nurses, attend an ELNEC course?

A: Yes! Other members of the interdisciplinary team are welcome to attend a national ELNEC train-the-trainer course. At most every course there is a wide-variety of healthcare professionals who attend. For example, chaplains, social workers, physicians, speech therapists, physical therapists, etc. have attended. Remember, this is a train-the-trainer course and everyone should attend with the intent of sharing the curriculum with others.

Note: For 5 or more that attend from the same institution, a \$25 registration discount is given for each attendee.

Please do not hesitate to contact me if you have any further questions about ELNEC training.

Sincerely,

Pam Malloy
ELNEC Project Office
American Association of Colleges of Nursing (AACN)
Washington, DC
202-463-6930, Ext. 238
pmalloy@aacn.nche.edu



RESOURCES



Three years ago, the ELNEC-PPC project worked with Cure4Kids to help develop the ELNEC-PPC online course for nurses internationally. This course has reached thousands of nurses globally. A new Cure4Kids initiative called Oncopedia has been developed to enhance pediatric hematology/oncology content and increase interactivity among users. Oncopedia will have three main sections.

First, complex or unique clinical cases submitted by Cure4Kids users will be posted in Oncopedia, and all users are welcome to add opinions and comments. Second, experts in the field of pediatric hematology and oncology will be invited to contribute disease-specific content. Finally, Oncopedia will contain a large collection of images submitted by users illustrating typical findings in pediatric oncology, hematology and infectious diseases. These images will be available for use in presentations, lectures and other educational activities. The images can be downloaded directly into PowerPoint and will contain the names of the contributors. All material submitted to Oncopedia is peer reviewed via a Web-based process.

- **Center to Advance Palliative Care (CAPC)** provides palliative care leadership centers. If you are looking for hands-on training to begin a palliative care center at your institution, with a full year of mentoring, go to: <http://www.capc.org/palliative-care-leadership-initiative/training-and-mentoring>.
- **Brand new WHO HIV/AIDS Treatment and Care Protocols for the European Region in Russian** is now available at: http://www.euro.who.int/eprise/main/WHO/Progs/SHA/treatment/20060801_1.
- For more resources, go to <http://www.aacn.nche.edu/ELNEC/resources.htm>.
- For a list of national and local ELNEC trainings, go to: <http://www.aacn.nche.edu/ELNEC/Upcomingtrainings.htm>.