

ELNEC Connections

Spring 2005

End-of-Life Nursing Education Consortium

Welcome to the Spring 2005 Issue!

The End-of-Life Nursing Education Consortium is pleased to bring you the Spring 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. ELNEC is administered through a partnership between the American Association of Colleges of Nursing (AACN) and the City of Hope National Medical Center (COH).

FIVE NATIONAL ELNEC COURSES TO BE HELD IN 2005

First 2005 Course Held in Long Beach, CA

On March 9-11, 117 nurses from around the United States attended an ELNEC-Core course. Nurses who work in hospitals, hospices, long-term care facilities, clinics and universities attended the first training offered this year. In addition, this was the first national ELNEC course offered that was not grant-funded. After completing this course, these staff nurses, continuing education providers, hospital nursing educators and undergraduate nursing faculty returned to their institutions to teach others how to care for those facing end-of-life issues.



Susan Lyons and Dawn Drooger from Washington County Hospital in Hagerstown, MD. Several participants came with their institutional colleagues to discuss dissemination and implementation of the ELNEC curriculum.

Washington, DC: Site of October 2005 ELNEC Course

Come to the nation's capital for a national ELNEC course to be held on the east coast. This course will be held October 28-30 at the Marriott Washington Dulles Airport Hotel. For more information on this course and to register, go to www.aacn.nche.edu/ELNEC. Deadline for registering for this course is September 1.



Third National ELNEC-Pediatric Palliative Care Training Program to be Offered in August 2005

If you are a pediatric nurse who needs training in pediatric palliative care, you will not want to miss this course on August 3-5 in Pasadena, CA. A copy of the registration form and other information on the course can be found at www.aacn.nche.edu/ELNEC. Deadline for registering is June 17.

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Two Additional Courses to be Offered in 2005:

- June 15-17: ELNEC-Graduate (course is full)
- September 14-16: ELNEC-Oncology
Deadline is May 18

Congratulations!



Congratulations to Judith Paice, PhD, RN, FAAN, research professor at Northwestern University and ELNEC faculty member on her recent election as President-Elect of the American Pain Society.

ELNEC-Pediatric

Nancy Diane Mannelli-Brewer, nmanelli-brewer@peacehealth.org

Hospice Care Manager, PeaceHealth, Eugene, OR

Tyson, an 11-year-old leukemia patient was asked by Nancy Diane if he could help her come up with a name for Sacred Heart's developing hospice program for children last fall. He was quick to answer: "It would have to be something spiritual," he said. He and his grandfather shared an interest in the stars and the cosmos; he suggested that the name say something about little stars. Tyson died just a few weeks later. Meanwhile, the program he named is allowing more and more terminally ill children in Eugene-Springfield to leave the hospital and live out their lives at home in the comfort of their family. Nancy Diane, founder of Little Stars, states that "people don't want to think about end-of-life care for children. It just doesn't seem right. But it does happen." Since completing her ELNEC-Pediatric Palliative Care training in 2003, Nancy Diane has been busy training other staffers in her community and institution.



Debbie Cagen Salani, Deborah.Cagen@mch.com

Miami Children's Hospital, Miami, FL

Debbie and Michele Franco, both ELNEC-trained, have developed a Palliative Care team of nurses who have shown special qualities of leadership in delivering end-of-life care to pediatric patients. The goal and objectives of this team are to educate, mentor and develop the nursing staff in providing a holistic palliative care approach, so that they can in turn mentor other staff in the hospital. Several staff members mentioned that they did not even realize or recognize that they possessed a unique talent or skill when interacting and interfacing with pediatric patients and their families as they progressed through the dying process. These staff members continue to be encouraged in mentoring newly hired as well as seasoned staff members. Another innovative, unique, and creative resource was the incorporation of a parent panel at their recent workshop. Three to four parents who lost their child from a variety of different conditions such as childhood cancer, trauma and genetic abnormalities, were asked to share their experiences with the staff. The staff found this to be incredible feedback and stated they learned so much from the parents as to what was helpful and meaningful to the parents and what was detrimental. By understanding this, staff can better interact with parents at their most vulnerable and tragic moments.



Maria Rugg, maria.rugg@sickkids.ca

Hospital for Sick Children, Canada

Over 60 nurses, physicians, chaplains, social workers and child life therapists have participated in a four-day pediatric workshop using the ELNEC curriculum. Maria also uses the ELNEC curriculum in general orientation for all nurses and holds an education session entitled "What Do I Say?" After reviewing the communication module, they teach nurses how to be with families when there is bad news and how to speak with children. In addition, Maria assists in teaching the pain, symptom management and communication modules to residents, community doctors and nurses who have little experience with pediatric palliative care.

Kay Frommelt, Kay.Frommelt@clarke.edu

Clarke College, Vancouver, Washington

Over Christmas break, Kay taught her first graduate course in ELNEC Pediatric Palliative Care. Eighteen nurses took this first course, with each nurse being required to teach a portion of the class.

Pediatric Palliative Care: Ethical, Legal and Practical Influences on Decision-Making

NHPCO May Audio Web Seminars

May 12, 2005, 2:00-3:30p.m. ET

Presenters: Brian Carter, MD, FAAP and Marcia Levetown, MD

This session will use a case-based format to illustrate the ethical dilemmas inherent in the care of a "never competent", terminally ill pediatric patient along the progression of development. In addition, the influences of parental guilt and grief, widely available invasive technologies, and healthcare perceptions of the laws on healthcare decision-making for severely ill children will be explored. Finally, language tools that more effectively communicate the realities of the child's options, minimize guilt and reduce dysfunctional grieving will be provided.



Seminar Objectives:

1. Explore the perceptions of children who are severely ill and their rights in the decision-making process and contrast these with parental perceptions and rights.
2. Discuss laws which impact the choices available to parents, children and caregivers faced with a child's life-threatening condition.
3. Provide approaches to communication regarding decision-making for and with children, including helpful phrases.
4. Recommended guidelines and considerations for resolving ethical tensions and value conflicts will be presented.

To register visit <http://www.nhpc.org>.

ELNEC-Oncology

Seven ELNEC-Oncology Participants will be Honored as Award Winners

On Wednesday, April 27, seven participants from the February 2004 ELNEC-Oncology course will be honored at the Chapter President's Reception at the Oncology Nursing Society's (ONS) 30th

Annual Congress. These seven nurses were chosen for not only their outstanding work in attempting to disseminate the ELNEC-Oncology curriculum to members of their ONS chapter, but also for their commitment to implementing much of the content into their daily nursing practice. The Award Winners for the first ELNEC-Oncology training program are:

- **Patricia Julian**, North Central West Virginia Chapter
- **Carma Erickson-Hurt** and **Marlon Saria**, San Diego Chapter
- **Mary Pat Johnston** and **Lori Wendt**, Southeastern Wisconsin Chapter
- **Carol Curtiss** and **Helen James**, Western Massachusetts Chapter

To read how these participants disseminated ELNEC content go to <http://www.aacn.nche.edu/el nec>.



Carma Erickson-Hurt, ecarma@hotmail.com
San Diego ONS Chapter

Carma, a Lt. Commander in the US Navy, is on board a hospital ship off the Northern coast of Sumatra near the tsunami-ravaged Banda Aceh. "I must say there has definitely been a role for palliative care here," states Carma. Not only has she been caring for people with injuries due to the tsunami, but has also seen people with advanced cancer. She has been able to provide some education to Indonesian nurses on pain control.

Mary Pat Johnston, marypat.johnston@phci.org
Southeast Wisconsin ONS Chapter (SWONS) End of Life Committee Co-Chair

The ELNEC-Oncology curriculum was presented on November 15 and 16, 2004 at the Olympia Resort and Conference Center in Oconomowoc, WI with 56 participants traveling from northern Illinois, southeastern Wisconsin, and north/central Illinois. This course was hosted by SWONS. In

addition, each attendee was invited to participate in a chapter study, entitled "Evaluating the Impact of End-of-Life Education on Nurses Caring for Oncology Patients with Advanced Cancer." A



Left to right:: Lori Wendt, Pat Coyne, Mary Pat Johnston at the ELNEC-Oncology course held in Oconomowoc, WI.

pre-and post-course knowledge survey was distributed to participants with a cover letter inviting them to participate in a study. The surveys are in the process of scoring and data analysis with results to be reported in an upcoming issue of their chapter newsletter.

Agnes Wong, AggieRN1@aol.com
San Francisco Bay Area ONS Chapter (SFBAONS) Board Member

Agnes reports that she and her teammate who attended ELNEC-Oncology with her in 2004, Michelle Gabriel, have plans to include their training in the following activities with their ONS chapter:

- "The Palliative Care Corner" – Agnes and Michelle will write a series of articles for their chapter newsletter over the next two years.
- Roundtable sessions – They are planning a series of roundtable dinner sessions to discuss the role of the oncology nurse in palliative and end-of-life care.
- Oncology Care Update – The chapter will offer an annual oncology care update.



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

For a complete list of upcoming trainings and course descriptions, check the ELNEC Web site at:
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 by May 24, 2005 for the Spring issue.**

Dana Buechner, Dbuechne@csc.edu

*Instructor, Columbus State Community College
Columbus, OH*

Dana has developed an end-of-life course based on the ELNEC program. She teaches the course weekly, as well as on-line. So far, 20 students have taken this course which includes field trips. In addition, Dana uses the ELNEC information in her own practice as a nurse practitioner. "It is amazing how many people come to my office with 'other complaints' and when you delve into the social aspects of their life, many are actually grieving!"

Marilyn Chan, mchan@westminstercollege.edu

*Director of the MSN Program, Westminster College
Salt Lake City, Utah*

Recently, Westminster College held an all-school seminar on end-of-life care. The Loss, Grief and Bereavement ELNEC module was used along with the video "Claire's Story." Marilyn reports that one nursing student wrote the following in her evaluation: "I thought the seminar was fantastic, informative, and very well organized. Since starting nursing school, I have had my doubts for the past 3 weeks if I have made the right decision. This seminar was the turning point that made me realize the value of being a nurse, and how I wanted to be a part of it."

Marilyn Stoner, mstoner@exchange.fullerton.edu

*Assistant Professor, California State University
Fullerton, CA*

Marilyn has written an article that will appear in the May/June issue of the *Journal of Hospice and Palliative Nursing* focusing on end of life care for practitioners of Tibetan Buddhism. The article will give palliative care and hospice caregivers specific feedback on how to support religious wishes at the end-of-life.



Helen Wilson, LWilson838@aol.com

*Alabama State Nurses Association
Wetumpka, AL*

Helen has covered the state of Alabama with her 3rd continuing education program on the end of life. Helen has found that including someone from the local area to assist her with the training improves the attendance. With her last training, she included a minister with expertise in grief counseling and a local hospice nurse. Helen also states that she has had good success with involving family members who are or have gone through the issues with end-of-life care.

Rita Mastroianni, rmastro1@jhmi.edu

*Johns Hopkins Hospital
Baltimore, MD*

Rita reports that she and her staff provide a palliative nursing workshop that is part of the core educational curriculum. The format is based on the ELNEC curriculum, but other educators from various disciplines also present. In addition, a palliative care workshop for critical care nurses has been provided. Examples of relevant topics include symptom management when withdrawing life support, the communication piece on dealing with specific family issues, as well as the conflicts that can arise among clinicians/families around end-of-life care in the critical care setting.

Connie Dahlin, cdahlin@partners.org

*Massachusetts General Hospital (MGH) Palliative Care Service
Boston, MA*

Connie and many of her colleagues are making a difference in providing end-of-life/palliative care education in the city of Boston. Here are some highlights:

- In the last two years, MGH has hosted five ELNEC training workshops. Various members of the interdisciplinary team have attended. An ELNEC training course will be held in 2005. As a preceptor to graduate students, Connie works with them to present an aspect of an ELNEC module as their final project for the semester.
- As a site of the Robert Wood Johnson Merging Palliative Care in the ICU, MGH intensive care unit is participating in changing their environment. Seven palliative care nurse champions are undergoing ELNEC training.
- At the Brigham and Women's Hospital, the entire nursing staff including the nurse manager voluntarily completed ELNEC training. Maureen Lynch assisted Connie with this training.
- St. Luke's Circle of Compassion had a 2 ½ day ELNEC training program in September 2004.
- The Harvard Center for Palliative Care holds an annual "Art and Science of Palliative Nursing" Conference. The content is based on the ELNEC curriculum. The June 2004 conference had both adult and pediatric components. This course will be offered again on **June 9-10, 2005**. For more details, go to www.masgeneral.org/palliativecare.

Inspiration, News & Resources

ELNEC Trainers Hold First Statewide Training in Hawaii

On March 12, 2005, ELNEC trainers Charon Pierson, ReNel Davis, Beth Freitas, Dianne Fochtman and Alyson Williams-Cheung presented the 9-hour training for nurses and other professional staff from all over the state. The participants included registered nurses, student nurses, home health aides, case managers, social workers, a nursing school dean, a chaplain, a physician, and two hospice volunteers. Because they had a diverse audience, organizers used breakout sessions in the afternoon to address the special needs of those for whom end-of-life care is a totally new concept, for those who work in pediatrics, and two additional groups of those who have more experience with the topic.



Clockwise L-R: Charon Pierson, Beth Freitas, Kathryn Braun, Ken Zeri, Joy Yadao, Alyson Williams-Cheung, Dianne Fochtman, and ReNel Davis

Planning for this statewide event began last year when Rachael Wong, coordinator for Kokua Mau, the statewide partnership for improving end-of-life care, contacted Charon Pierson to talk about how to best use the wonderful resources for ELNEC trainers throughout the state. After input from all the Hawaiian trainers, many meetings, and lots of emails, the date was set, the venue secured, and sponsorships arranged. In addition to Kokua Mau (which means "continuous care" in Hawaiian), sponsors included: St. Francis Hospice, Hospice Hawaii, Hawaii Pacific University, and the Pacific Islands Geriatric Center. Assisting the ELNEC trainers as faculty were Joy Yadao, RN, Executive Director of St. Francis Hospice, and Ken Zeri, MS, RN, President of Hospice Hawaii. Guest speaker Kathryn Braun, DrPH, a well-known author and researcher on cultural aspects of death and dying, presented the content on cultural considerations which she was enhanced with her own experiences researching these issues in the multicultural environment of Hawaii. The state of Hawaii now has 110 more health professionals who have received the full ELNEC training.



Trainers Take ELNEC Around the World

- Carol Kenner, Dean of Nursing at the University of Oklahoma, will be presenting a paper at the 6th International Russian Nurses Conference on pediatric end-of-life issues in August. Ckenner835@aol.com.
- Eldoret Hospice in Kenya, East Africa, was the setting for Marie Sines to take ELNEC Modules 1, 2 & 3 to the program director in December, 2004. mariesines@juno.com.

World Hospice and Palliative Care Day

The first World Hospice and Palliative Care Day will be observed on October 8, 2005. This will be a new unified day of action to celebrate and support hospice and palliative care around the world. Every year, millions of people around the world living with a terminal illness experience unnecessary pain and distress, either unaware of or unable to access the care they need. High quality hospice and palliative care which aims to meet the needs of the whole person can and does provide an answer. This is an issue that affects literally everybody on the planet – we would all like our lives – and the lives of those we love – to end peacefully and comfortably. For more information, go to www.worldday.org.

Palliative Care Leadership Centers

The Palliative Care Leadership Centers are celebrating their first anniversary and accepting applications for 2005 on-site training and mentoring. A full 97% of visitors at six sites recommend the trainings to palliative care advocates seeking assistance in fast-tracking their programs. If you are interested in learning more about a Leadership Center, go to www.capc.org



Speaking the Language

Need assistance in language interpretation and translation? Check-out Language Line at <http://www.language.com/home.php>.



Waltzing the Reaper, a One Woman Play

Are you looking for a unique way to provide information to your staff regarding end of life issues? Judith Gantly performs a one-woman play entitled, "**Waltzing the Reaper,**" a moving story about one woman's struggle to be able to die at home under hospice care. The play concerns a once-vital, still witty woman, Vera, who has been resuscitated despite her living will. Now she must depend on a relative she never liked to get her out of the hospital and home where she can make peace with her family and die with dignity. For more information, contact Judith at judithann13@earthlink.net or 908-687-6494 or check-out her website at www.judithgantly.com

