END-OF-LIFE NURSING EDUCATION CONSORTIUM

### **2011 ELNEC AWARD WINNERS**

#### **ELNEC-Core**



Diane C. Parker, RN, MSN, NE-BC, CHPN is the Chief Nursing Officer (CNO) at Hospice Care of South Carolina. She originally began her nursing career in critical care. She has over 20 years of Nursing Education and Nursing Executive experience. Over the past 5 years, Diane and her colleagues have held 3 ELNEC training courses, which have led to 500 interdisciplinary team members in her community and state being trained to provide better care for those with life-limiting illness in 2011 alone. Her commitment to end-of-life care (EOL) is demonstrated not only by her board certifications including Nurse Executive

and Hospice and Palliative Care Nurse, but also through her commitment to the advancement of EOL care across the lifespan. Recognizing a special need for a comprehensive pediatric service, she developed the Hands of Hope Comfort Care Program as a pediatric service of Hospice Care of South Carolina and moves forward in the development of community based Pediatric Palliative Care and Perinatal Hospice Care Programs for the state's best practice. She formed an internal interdisciplinary pediatric resource team to serve as a support statewide to the organization and integrated the principles of ELNEC-Pediatric Palliative Care (PPC) as a framework, building the state's only comprehensive pediatric hospice and palliative care program. Diane is an ELNEC-PPC, ELNEC-Core, and ELNEC-For Veterans trainer. As a result of her commitment to provide excellence in EOL care, The National Board for Certification of Hospice and Palliative Nurses (NBCHPN) has awarded Hospice Care of South Carolina the NBCHPN 2012 Employer of the Year Award. Diane represents South Carolina on the National Hospice and Palliative Care Organization Pediatric Policy Networking Group and Public Policy Committee and is currently working with regulatory and legislative professionals to change the face of pediatric care and reflect true patient-centered, family focused care. Diane took an entire leadership team to the ELNEC Summit in San Diego in January 2011. The goal was to develop faculty to teach all ELNEC courses and improve education not just on a local level but as a statewide resource. Having faculty available to teach any ELNEC course or its components reflects the organization's mission and is a vehicle to use in many ways. "ELNEC has helped change the way we think, learn, communicate, and collaborate. It is now our culture. We don't settle for anything less than excellence," stated Diane. If you would like to contact Diane, she can be reached at diane.parker@hospicecare.net

#### **ELNEC-Pediatric Palliative Care**



Vanessa Battista, RN, MS, CPNP, CCRC is a clinical faculty member at Boston College William F. Connell School of Nursing and works as a pediatric nurse practitioner in the Department of Neurology at Children's Hospital Boston. Vanessa has been committed to improving palliative care for all children. She understands the importance of education and instills knowledge about this care to her students and to practicing nurses by using the ELNEC-Pediatric Palliative Care curriculum. Vanessa teaches in the Pediatric Palliative Care Program at Boston College, which allows Advance Practice Nursing students

the opportunity to receive didactic and clinical education in the specialty of care. As part of this program, she helped organize a pediatric regional conference in Boston in October, 2011. National speakers shared their expertise on this care with 140 participants. Vanessa believes that in order for pediatric palliative care to be effective, the care must be interdisciplinary; thus when teaching, whether at the college or in the clinical setting, she reaches out to those from other disciplines. Vanessa's leadership and vision have included opportunities to embed pediatric palliative care into the nursing curriculum at Boston College. She speaks frequently to undergraduate and graduate nursing students, psychology classes, and was invited recently to speak at the Mendall Society and the business school on campus. "It is very exciting to teach people more about pediatric palliative care and to see the 'light bulb go on,' so to speak, as people see ways in which they can blend this into the work they do and recognize that palliative care is necessary everywhere," stated Vanessa. Vanessa may be contacted at vanessa.battista@bc.edu





Kelly Fischer, BSN, CHPN (left) and Kris Simon, BSN, LPC, CT (right) are two women who are committed to improving palliative care for children in Wisconsin (WI). Both co-founded *Bear Courage*, an organization, dedicated to educating nurses, physicians, and counselors about pediatric palliative care. They are organized and are working their way throughout the five Department of Health and Family Service regions of WI. *Bear Courage* began when Kelly and Kris realized that seriously ill

children do not have the same opportunities for home care that adults have. They found out that there is an even bigger gap in care for children in rural communities. *Bear Courage* established the Bear Courage Coalition in the state of WI with the goal of increasing collaboration and support among all agencies that provide care for seriously ill children. In their initial training in Jefferson County, they taught staff from three different hospice and home care agencies. The training was for an interdisciplinary audience and included nurse practitioners, nurses, social workers, chaplains and clinical nursing assistants. At the beginning of the ELNEC training, all participants reported feeling nervous and unsure about caring for seriously ill children. At the end of the two day training they all reported feeling excited, better prepared and well-supported. Beside holding the ELNEC-Pediatric Palliative trainings throughout WI, their work with the *Bear Courage* Family Advisory Board allows them to assess the

needs of those care providers in the home. In addition, the *Bear Courage*Coalition continues to provide in-depth education and support for *Bear Courage* trained practitioners to sustain clinical practice changes. Other *Bear Courage* programs include Family-2-Family, a monthly support groups,
bringing together families of seriously ill children for support and education.
Courageous Steps: Hope for Grieving Parents is a group for parents whose
child has. Future plans include starting a group to meet the unique needs of
siblings and grandparents of seriously ill children. After a year and a half of
extensive research and development, and becoming operational 7 months
ago, *Bear Courage* has learned how challenging it is to provide excellent in
home pediatric palliative care. There are multiple barriers that need to be



addressed. *Bear Courage* needs the support of ELNEC and all the ELNEC trained pediatric providers in Wisconsin to collaborate successfully to move the *Bear Courage* Collaborative Model forward and provide the children and families of Wisconsin the care they deserve. To read more about this project, go to <a href="www.bearcourage.com">www.bearcourage.com</a> You may contact Kelly and Kris at <a href="mailto:bearcourage@gmail.com">bearcourage@gmail.com</a>

### **ELNEC-Critical Care**



Elissa DeWolfe, RNC, MN, CNS, ACHPN attended a national ELNEC-Critical Care train-the-trainer course in April 2007. She also has received training in ELNEC-Pediatric Palliative Care, and ELNEC-Core. From 2010 until the end of 2011, Elissa worked at Sutter Care at Home in Santa Rosa, CA as a hospital liaison. While at Sutter, Elissa taught two ELNEC training courses in which 60 participants attended. She attended daily rounds in the ICU and was available for consultative services, assessing for patients who would be candidates for palliative care, pain and symptom management. She assisted in developing palliative care ICU order

sets and supported the development of referral processes for palliative care consults. Elissa assisted with discharge planning of in-patients to both hospice and AIM (Advanced Illness Management-palliative home care) programs. In November, 2011, Elissa began working as a Palliative Care Clinical Nurse Specialist (CNS) at the Kaiser Permanente Medical Center in Oakland, CA. She will develop palliative care programs in critical care areas such as pediatric ICU, neonatal ICU, as well as the 33-bed pediatric unit and the 39-bed labor and delivery department. Her eventual goal is to implement and provide palliative care in clinics, home health and hospice, so that care for these patients will be seamless. To begin this work, she knows that the interdisciplinary staff must be educated. She plans to roll-out ELNEC-Core, ELNEC-Pediatric Palliative Care, and ELNEC-Critical Care hospital-wide. Elissa can be contacted at elissa.m.dewolfe@kp.org

## **ELNEC-Geriatric**



Patricia Trotta, RN, MSN, CHPN is currently a Clinical Nurse Specialist in education and pain management for VNA Healthcare's Hospice/HOPE team in Waterbury, Hartford and Central Connecticut (CT). Previously Pat was coordinator for the Connecticut Cancer Partnership and manager of the New England Pain Relief Project of the American Cancer Society. She is a founding co-chair of the Partnership's Palliative and Hospice Committee and helped develop the palliative and hospice goals and objectives for both the 2005 – 2008 and 2009 – 2013 Connecticut Cancer Plans. A board member of the Coalition the Improve End of

Life Care for many years, she now serves as clinical coordinator for the Coalition's two recently funded Partnership/DPH grants to educate Connecticut health professionals in end of life care. The first statewide ELNEC –Geriatric Train-the Trainer Program, funded by a CT Cancer Partnership grant from the CT Department of Public Health, was held October 20 & 21, 2011, in a central location in Connecticut. Fifty nurse educators from nursing homes, home care agencies, hospices, hospitals & schools of nursing attended. As a requirement of participation, the new trainers committed to returning

to their communities/institutions & offering end-of —life education programs. Pat is quick to give gratitude to The CT Cancer Partnership (<a href="http://ctcancerpartnership.org/pages/welcome.asp">http://ctcancerpartnership.org/pages/welcome.asp</a>) and the CT Coalition to Improve End of Life Care (<a href="http://www.ctendoflifecare.org">http://www.ctendoflifecare.org</a>). Pat is grateful for Nealy Zimmermann, Elizabeth Ercolano, and Carol Curtiss who continue to do this work with her. You may contact Pat directly at <a href="mailto:patrotta@gmail.com">patrotta@gmail.com</a>

### **ELNEC-For Veterans**



Benito Garcia, BSN, MSN, is a nurse practitioner with the Palliative Care Service at the George Whalen VA in Salt Lake City, UT. Benito attended the very first national ELNEC-For Veterans train-the-trainer course in 2010. Benito has been very busy providing ELNEC courses to his staff. To date, 41 people have received ELNEC-For Veterans training from Benito and 14 of those have completed the entire training. Benito states the tools from the ELNEC curriculum have assisted him in increasing his own palliative care knowledge, as well as providing tools for him to educate others. Benito has been diligent in educating other staff, to assist in promoting excellent palliative care

throughout the VA facility in Salt Lake City, UT. In addition, he has shared this work at the November 2011 UT Hospice and Palliative Care Organization Conference. He provides monthly presentations to Holistic Medicine staff and volunteers. Benito would also like to acknowledge that a very special volunteer, Marlene Mickelson contributed many hours in making the ELNEC-For Veterans so successful in Salt Lake City. You may contact Benito at <a href="mailto:benito.garcia@va.gov">benito.garcia@va.gov</a>





Marcia LaHaie, RN, BSN, APRN-BC (left) and Linda Seck, RN, MSN (right) compassionately assess and care for Veterans at the VA Ann Arbor Healthcare System in Ann Arbor, MI. They have presented ELNEC-For-Veterans classes to diverse groups of nurses (RN, LPN; inpatient, outpatient) and other disciplines both within the VA and to outside facilities in

2011. Attendees reported improvement in their knowledge of end of life issues and communication skills and appreciated the chance to learn about and discuss alternative viewpoints. "We have seen evidence of improved knowledge of pain and other symptom management in interactions with nursing staff. We have also seen more independence in the social workers helping the medical teams identify patients who would benefit from a palliative care team or hospice referral," stated Marcia. You may contact Marcia at lahaie4@gmail.com and/or Linda at linda.seck@va.gov



Sheila Lozier, RN, BSN has worked for the past 17 years in Hospice/Palliative Care at Bay Pines VAHCS in St. Petersburg, FL. Sheila has been busy overseeing over 140 staff who have completed viewing ELNEC-For Veterans on the Hospice Education Network (HEN). In addition, she taught a 1-day workshop on end-of-life care with St. Petersburg College and facilitated a 2-day outreach program in her community with over 300 Veterans and their families being educated on hospice access. Sheila has seen the look of fear in the eyes of many Veterans as they begin their final journey. For many

years now the story has always been the same, "my doctor, my nurse, my healthcare provider did not tell me how sick I was," or "don't tell my wife/husband I'm dying." Sheila believes that all of these fears have robbed many Veteran hero's and their loved ones of sacred time to say good-bye and has left them to suffer in silence. ELNEC-For Veterans has provided a light and a means for educating care providers, volunteers and even families on how to start those conversations and how to bring honor and peace to these veteran hero's. "As a Veteran myself, I hope this grassroots effort will continue to melt away those looks of fear in the Veterans we serve and more selfishly that the healthcare system will finally 'get it right' when it's my turn for that final journey," states Shelia. You may contact Shelia at sheila.lozier@va.gov

# **ELNEC-International**



Juli McGowan, RN, MSN, FNP, is a hospice nurse practitioner at Kimbilio Hospice (means "refuge" in Swahili) in Kipkaren, Kenya and is the International Director of *Living Room Ministries International (LRMI)*. In 2009, she helped to organize LRMI, a non-profit organization that mobilizes people in rural villages of Western Kenya for HIV testing and treatment, provides HIV training, prevention, and offers home-based care for people living with HIV/AIDS and orphans. LRMI was established to address the many injustices that remain for those living with life-limiting illnesses in Kenya. Juli works long hours caring for children and adults

with life-limiting illness, dedicated to addressing not only physical needs, but also psychological, social and spiritual needs. She works tirelessly to train those she feels privileged to work with. She hosts student healthcare providers from various parts of the world who want to get experience in hospice care, and in her spare time last year, Juli worked hard to open a 26-bed, inpatient hospice that houses adults and children living with terminal illness. Kimbilio Hospice opened its doors in May of 2011 with the goal of offering palliative care services within the community. Their services include management of pain and other symptoms and provision of support for not only the patient, but for their family members, too. To date, Juli has used ELNEC to train approximately 20 interdisciplinary team members at Kimbilio Hospice. "We are learning how to provide holistic care within the context of Western Kenya and hoping to offer this training to other health-care workers living in Kenya in 2012," stated Juli. "Since its inception, LRMI has reached out to many among our community who are not only faced with terminal illnesses but also lack the love and care that signify human dignity." You may contact Juli at juli@livingroominternational.org For more information about Kimbilio Hospice and LRMI go to www.LivingRoomInternational.org.



The Team at Hospice Casa Sperantei, Brasov, Romania. Hospice and palliative care nursing is based on a team effort, and it is certainly evident with the nurses, physicians, social workers and chaplains at Hospice Casa Sperantei in Brasov, Romania. But for every team to grow and to be educated to do this sacred work, a leader must emerge. Though there are many who are leading the way in

Romania to improve palliative care, Nicoleta Mitrea, heads the education of the palliative care nursing team at Casa Sperantei and throughout Romania and the Balkan Region. Nicoleta wears 4 hats in promoting this care throughout the region. She is actively involved in organizing, supervising, and teaching palliative care. She is also the program coordinator for the "East-East: Partnership Beyond Borders Program," financed by the Open Society Institute (OSI) throughout Romania, Republic of Moldova and Serbia. Thirdly, Nicoleta supervises the intermediate level of palliative care education for nurses via CEU's throughout Roman. Casa Sperantei is the only institution authorized by the Romanian National Order for Registered Nurses to deliver Palliative Care continuing education for nurses. Finally, Nicoleta is the project manager of the grant "Advanced Training for Nurses in Palliative Care," which is committed to developing a curriculum in palliative nursing, based on the ELNEC-International materials. Those who work at Casa Sperantei understand the rich heritage of this special place. Founded in 1992, Casa Sperantei began life with an office of one nurse treating terminally ill patients for the first time in Romania. As well as palliative care at home, in 2002, Romania's first in-patient hospice was opened to treat and manage patients' illnesses and symptoms for a maximum of two weeks at a time. The hospice has beds for 13 adults and up to 6 children at any one time. In addition, medical teams of doctors, nurses and social workers make visits to patients and families in their homes daily. The hospice also has an out-patient clinic for children and adults, as well as a day centre. The hospice is now regarded as a Centre of Excellence for South-Eastern Europe. In addition, the Princess Diana Education Centre in Brasov was opened in 1997 to provide hospice resources and training courses to medical, nursing, and social work professionals from all over South-Eastern Europe. Much has been accomplished in Romania

since 1989, when the Romanian people tore their country free from 50 years of communist dictatorship. Yet, those who work at Casa Sperantei would be the first to say that there is still much work to do. One important "task" that needs to be completed is translating ELNEC-International into Romanian. Under the leadership of Nicoleta and her team, from left to right: Roxana Horeica, Nicoleta Mitrea, Gabriela Burlacu, Camelia Ancuta and Teodora Mathe, this work is almost completed. For more information about Hospice Casa Sperantei, Romania go to <a href="www.hospice.ro">www.hospice.ro</a> and <a href="www.studiipaliative.ro">www.studiipaliative.ro</a>. Nicoleta can be contacted at <a href="micoleta.mitrea@hospice.ro">nicoleta.mitrea@hospice.ro</a>

