Welcome to our first issue of the NEPIG News. We want to share with you the exciting efforts of this active ad hoc special interest group which works to advance palliative care through education, outreach, activism and research.

JOIN NEPIG Become an active member! We want this group to continue growing and becoming increasingly sustainable. We meet on monthly basis to discuss and work on a variety of projects. Please share your input and ideas with us. Let us know how you would like to contribute. To join NEPIG or discuss your interest, please contact Raeann at rgleblan@nursing.umass.edu or Olga at oehrlich@nursing.umass.edu.

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization Definition, 2017)

CONGRATULATIONS
February 8, 2017. Olga Ehrlich, NEPIG Chair, successfully defended her PhD dissertation - *Cancer Pain Processes in the Hospice Caring Triad: A Grounded Theory Study*, making a significant contribution to the understanding of social processes in pain management. To learn about the behaviors, thoughts and meanings associated with end stage cancer pain, patients along with their family caregivers and hospice nurses were interviewed privately. Over the course of multiple interviews and observational visits for each caring group, Ehrlich discovered that key elements of the nursing process were not always occurring in routine pain management behaviors. By applying constructivist grounded theory research methods, she created a framework for nurses and researchers to use when managing cancer pain in the context of hospice care. Further, she identified a need for the development of assessment tools that help members of the hospice caring group identify functional pain goals for use in care planning. She plans to develop such assessments and test them for usability and efficacy in her next stage of research.

EDUCATION UPDATE
**Palliative Care Information to Support Practice Website** - https://www.palliativepracticesupport.info/

December 2015 -September 2017, an education project that is coming to completion is the web-based learning initiative **Palliative Care Information to Support Practice**. This project began in 2015 by Raeann LeBlanc who received funding for the project, organized the project and designed the website. This project was inspired as part of an action plan following attendance at the End of Life Nursing Education Consortium (ELNEC). The project is an evidence-based
website with educational modules that offers a general overview of palliative care and a focus on palliative care communication for nursing. This project was also inspired by the 2014 legislation in Massachusetts (House Bill 2104 – An Act to Expand Access to Palliative Care) requiring nursing as a profession to communicate to patients their palliative care options. The website was a collaboration of nurses including honors student and now RN, Alexis Boumis, DNP graduates and community-based palliative nurses -- Diane Davis and Kaveri Roy, PhD Olga Ehrlich and faculty Raeann LeBlanc, DNP & Rachel Walker, PhD. The website and the modules are free has been approved for CEUs from the American Nurses Association that will close this month. The costs for the project and ANA Fees were partially supported by a small grant from the Massachusetts Society of Professors. To date almost 100 healthcare professionals have completed the self-study and taken up the call to activate their learning in their practices. Following September will be analysis of this educational project and plans for the next steps. Would you like to contribute your ideas to a web-based learning project or tools for practitioners? Let us know at NEPIG or contact Raeann at rgleblan@umass.edu.

Let’s Talk – The D-Word: How Can We Compassionately Talk About Dying? September 2017, A new course has been added to the Honors College. This course focuses on communication and the choices people make in the months and days leading up to dying, how this impacts the dying experience, and what this means for those they leave behind. Talking about dying and loss is frightening when we do not have the skills to do so with empathy and compassion. Regardless of whether we work in health-related or other fields, every one of us has or will encounter death and loss. How do we honor the choices of others and help create a meaningful and dignified experience for people going through this process? In this seminar, you will have the opportunity to explore your ideas and preconceptions about how people die and why they make the choices they do. Participants study culturally-relevant practices related to death and dying, specifically related to communication. Learning activities will include research and writing on topics related to dying, guided exercises in talking about end-of-life choices, and a research project. Students will explore the impacts that talking about dying has on the health of individuals, communities, and societies.

EDUCATIONAL RESOURCES – RECOMMENDATION – AN LGBTQ FOCUS


POLICY UPDATE

Palliative Care and Hospice Education Training Act. April 14, 2017, Olga Ehrlich and Maureen Groden met with U.S. Representative Jim McGovern and his staffer Keith Barnicle at his office in Northampton, MA. Groden and Ehrlich thanked the Congressman for his co-sponsorship of the PCHETA bill (see Palliative Care and Hospice Education and Training Act: S. 693/ H.R. 1676 below). Discussion also focused on 1) the importance of the Medicare Hospice Benefit with the current interdisciplinary approach, as opposed to a Medicare Advantage carve-in benefit; 2) the definition and difference between Palliative Care and Hospice; 3) the importance of Advanced Directives and early discussions with patients with serious illness; and, 4) the imperative of having expert educators and clinicians trained and prepared to care for the growing demographic of Americans over the age of 65.

PALLIATIVE CARE AND HOSPICE EDUCATION AND TRAINING ACT: S.693/ H.R.1676 (PCHETA)

The PCHETA bill amends the Public Health Service Act to require the Department of Health and Human Services (HHS) to provide support for Palliative Care and Hospice Education Centers. These centers must improve the training of health professionals in palliative care and establish traineeships for individuals preparing for advanced education nursing degrees, social work degrees, or advanced degrees in physician assistant studies in palliative care. HHS may provide support to schools of medicine, schools of osteopathic medicine, teaching hospitals, and graduate medical education programs for training physicians who plan to teach palliative medicine.

HHS must: (1) provide Palliative Medicine and Hospice Academic Career Awards to individuals to promote their career development; (2) support entities that operate a Palliative Care and Hospice Education Center; (3) support advanced practice nurses, social workers, physician assistants, pharmacists, chaplains, or students of psychology pursuing an
advanced degree in palliative care or related fields; and (4) award grants to schools of nursing, health care facilities, or programs leading to certification as a nurse assistant to train individuals in providing palliative care.

The Agency for Healthcare Research and Quality must provide for a national education and awareness campaign to inform patients, families, and health professionals about the benefits of palliative care. The National Institutes of Health must expand national research programs in palliative care (Congressional Research Service, Library of Congress, 3/22/2017).

**CONGRESSMAN McGOVERN JOINS FISHER HOME AND UMASS TO SUPPORT HOSPICE**

UMass Nursing partnered with Hospice of the Fisher Home and invited U.S. Representative Jim McGovern and his aides to an event at the Fisher Home to celebrate the successful collaboration and to educate the Congressman on hospice care. The event began with a tour of the beautiful, home-like, 9-bed hospice residence. Congressman McGovern then met privately with one of the hospice residents Ellen. They both sat out on the side porch and enjoyed conversing about hospice, and also realized that they had some shared roots in the Worcester area.

Representatives from the Fisher Home, UMass, and McGovern then convened in the living room for a short program. Liz Weissbach, Executive Director of Hospice of the Fisher Home welcomed everyone. She stated that working at the Fisher Home doesn’t feel like a job, it’s a passion. She thanked her fellow employees for their dedication to the home. She introduced Maria Rivera, the Clinical Director. Rivera thanked everyone for coming to the event. She also thanked UMass for the successful clinical placement relationship and introduced Maureen Groden, UMass Clinical Faculty. Groden also thanked everyone for coming and thanked Congressman McGovern for his support of health care and hospice care in particular. Groden has placed Accelerated Nursing Program students at Hospice of the Fisher Home for their community nursing clinical. It has been a mutually beneficial relationship and an excellent learning experience for nursing students.

UMass Nursing & Hospice of the Fisher Home Representatives gather with Congressman McGovern on July 7, 2017

UMass Nursing representatives shared information with the attendees on several topics. Donna Zucker, Associate Dean for Academic Affairs, brought greetings from UMass and spoke about the successful nursing programs currently at the flagship UMass, Amherst campus. Maeve Howett, Assistant Dean of Undergraduate Nursing Education, expressed gratitude for the event and for the clinical placement relationship. Two current Accelerated Nursing students, Gillian Cannon and Kelly Schatz both spoke about the invaluable clinical placement in hospice. Cannon was a student this Spring at the Fisher Home.
She cared for a patient in the community that then transferred to the residence. The experience definitely made her interested in this area of nursing in the future. Kelly Schatz spent her community clinical at the Soldier’s Home Holyoke’s 21-bed unit for veterans who are at end of life. Schatz said she has seen first hand how care at these hospice facilities differs from care at other places. Quite honestly she said, she can see the importance of education and training on end of life care and conversations about advanced directives. That is exactly what Olga Ehrlich, recent UMass nursing Ph.D. graduate, spoke about: the importance of adequate numbers and expertly trained faculty to teach clinicians of the future on hospice and palliative care. Ehrlich spoke about the PCHETA bill (see Palliative Care and Hospice Education and Training Act: S. 693/ H.R. 1676 above). She also brought handouts on the bill and urged attendees to write to their representatives in Congress to support this important legislation. Raeann LeBlanc, Clinical Assistant Professor, spoke about the development of NEPIG, and gave an update on all the activities and accomplishments of this nursing group.

Congressman McGovern thanked everyone for the invitation and for their important work in hospice. He commented that he wished every member of Congress would take the time to get to know the human beings, such as Ellen, who are the ones affected by all the legislation presented to Congress instead of primarily dealing with the flood of paperwork that passes through their offices. He also made a commitment to co-sponsor the recent version of the PCHETA bill. Congressman McGovern represents the 2nd Congressional District in Central & Western MA, including Amherst, and is serving his 11th term. He is an unwavering supporter of social justice, human rights, and health care reform.

RESEARCH UPDATE
The study entitled *Measuring Undergraduate Nursing Student Knowledge in Palliative Care Delivery-A Pilot Study* has been completed by the research team Olga Ehrlich, PhD, Raeann LeBlanc, DNP, Lisa Chiodo, PhD and Erin Lamothe, MSN. The findings will be presented at the California State University Institute Palliative Care Conference (see below) an exciting event taking place this September. For more information look forward to an update on the outcomes of the study and highlights from the conference in our Next NEPIG News.

PUBLICATIONS
Roy, K., LeBlanc, R. Wong, (2017-accepted). Addressing refractory dyspnea in advanced COPD with patients and their caregivers: A feasibility study. *Journal of Hospice and Palliative Care Nursing*


UPCOMING EVENTS – CHECK THESE EVENTS OUT – NEAR AND FAR

**Thursday, Sept. 28-Friday, Sept. 29** - San Diego, CA – CSU Palliative Care National Symposium for Academic Palliative Care Education & Research [https://csupalliativecare.org/symposium/](https://csupalliativecare.org/symposium/)

**Tuesday, Nov. 7 -Thursday, Nov 9.** - Norwood, MA – Hospice and Palliative Care Federation of Massachusetts Conference [http://www.hospicefed.org/event/2017EC](http://www.hospicefed.org/event/2017EC)

**Thursday, Dec. 7 – Sunday, Dec. 10, 2017** - Naropa University, Boulder CO -- Compassionate Approaches to Aging and Dying – Transforming the Paradigm of Care [https://www.enaropa.org/event/compassionate-conference/](https://www.enaropa.org/event/compassionate-conference/)