State of Maine Palliative Care and Interdisciplinary Quality of Life Advisory Council
Minutes from meeting on November 16, 2018, held by conference call due to weather

Council members attending by phone: Elizabeth Keene, Lauren Michalakes, Peggy Belanger, Kandyce Powell, Greg Burns, Dennis Fitzgibbons, Kevin Lewis, Jim Vankirk, Jeff Aalberg

Guests: Scott Fish, Jane Conrad

Report on Council membership Kandyce Powell stated that, in order for there to be a vacancy on the Council, which can then be filled, the rules require that anyone stepping down must submit an official statement to State government. (For example, she needs a written statement from Dr. Condit.) Also, anyone willing to continue at the end of their three-year appointment should indicate in writing their willingness to continue. Presently there are a number of unfilled vacancies and pending appointments. It is hoped that once the new administration and legislature transition, these appointments will be made and the work of the Council will be enhanced.

Report on Social Media Proposal The palliative care legislation states that there should be comprehensive, accurate information and educational programming available to the public regarding palliative care. The general public and even individuals working in long-term care are not sufficiently aware of the benefits of palliative care. There is some information available now on the Hospice Council’s website, but Scott Fish and Kandyce Powell believe that we may be able to secure funding to expand and further promote palliative care via social media. Scott’s organization, the Maine Seacoast Mission, is interested in promoting public service announcements and other video clips on Youtube. (To see the information available on his organization’s website go to: seacoastmission.org/ourstory)

April is hospice and palliative care month and Scott hopes to collaborate with hospice groups to film some TED talk clips.

Legislative update – Hilary Schneider was unable to attend today’s meeting due to a flight delay. Jim Van Kirk and Kandyce Powell reported. There were several Op.Ed. pieces regarding Question One on the ballot (funding for home care for the disabled and elderly). The Hospice Council issued a press release supporting the idea in principle and a willingness to work on this issue legislatively. The Home Care Alliance published an Op.Ed. piece opposed to Question One.

Jim and Kandyce co-authored an Op. Ed. Piece in support of PCHETA.
There were a number of groups staffing tables in polling places to gather signatures for physician assisted suicide/death with dignity legislation. It is unknown whether they collected the requisite number of signatures. The American Medical Association remains opposed to such legislation. While many members of this group feel that having choices at the end of life is appropriate, it is important that the work of this Council not be overshadowed or linked to proposed legislation on physician-assisted suicide, which is a separate issue from providing palliative care and hospice services to those dying of natural causes. Our purpose is to broaden awareness and promote such care and services.

Lauren Michalakes reported on visits to the offices of our United States Senators in Washington to discuss the proposed Palliative Care and Education Training Act. The Senators’ staffs indicated that the current legislative health priority is opioid addiction, but Lauren was encouraged by the positive response of both Senator Collins’ s and King’s offices to the proposed legislation.

Peggy stated that the American Cancer Society feels that progress is being made on this legislation since it has been approved in Congress three times, despite the inaction by the Senate. Those present were urged to contact their senators to support the legislation.

It was observed that the FDA recently approved a new drug for use in palliative and end-of-life care. There remains significant work to be done in educating people that it is appropriate to use opioids to treat those in palliative and hospice care.

**Rural Access Update**  Kandyce Powell reported that there is an informal group of service providers in Jackman that is meeting monthly to put together a new model of care to help residents age and die in place since there is no longer any LTC facility in that area. There is a terrific educator, Denise Plant, facilitating the group. The islands are considered rural. There is a group in Islesboro that has been addressing rural access challenges. Lauren reported that Pen Bay and Waldo hospitals provide services to the mid-coast islands, and providers on the islands have been invited to participate in Project ECHO. These groups should be invited to collaborate and share ideas with other rural areas to improve access to palliative care services.

**Report on Pediatric Palliative Care**  Greg Bruns reported on a recent subcommittee meeting of the pediatric palliative care initiative. Northern Light is beginning a pediatric inventory in their Home Health and Hospice offices to understand current pediatric activity and assess training needs. Offices in multiple counties cover a wide swath of the state from York to Aroostook County. There is support for clinician
training and pediatric palliative service delivery and the subcommittee suggests that the Pediatric ELNEC curriculum be used as the foundation for a statewide training of 1 or 2 days to be held in the fall of 2019.

**Report on Payer Pilot** Lauren Michalakes reported on reimbursement methodologies discussed at the recent Center to Advance Palliative Care (CAPC) annual conference. The goal is for palliative care to be reimbursed in the manner that hospice benefits are reimbursed through private insurance, Medicare and Maine Care. A significant obstacle to a reimbursement scheme is that there have to be qualifying palliative care programs in place in order to seek reimbursement for services. Many parts of our state do not have full-fledged inter-disciplinary palliative care programs. For example, Dr. Michalakes’s palliative program in the mid-coast provides care to hospital patients and out-patient visits, but there is no home-care component. Most insurers only reimburse services provided by a nurse practitioner or physician and do not cover case management by nurses or spiritual/mental health services by social workers or chaplains, all of which are key to successful palliative care programs.

The ASPIRE program which provides reimbursement in some other states was purchased by Anthem. It is based in Nashville, a high-density population area, and includes a nurse practitioner, a case manager, and home-based care. The program reimburses providers for goals of care conversations, home visits and 24-hour telephonic support. We do not have a program like ASPIRE in Maine. Kevin suggested that perhaps his company and Dr. Michalakes might fashion a pilot payer-provider-member program. They will explore this further. Also, Lauren will talk to Anthem’s oncologist about what they are thinking about possible reimbursement methods for palliative care.

**Update on Project ECHO** Project ECHO is a telehealth hub and spoke platform for addressing specific health care issues. Maine Health first implemented a Project ECHO for endocrinology and will launch a palliative care Project ECHO in January 2019. While this is a MaineHealth system program, all interested providers are invited to participate. Dr. Michalakes’s office in Rockport will serve as the “hub” for the program and other providers and interested parties are the “spokes”, all of which will be linked by video conference. The session includes an initial didactic presentation, then a discussion of one case per monthly session. The sessions will be held at 7:30 a.m. on the first Thursday of each month. (Contact Lauren Michalakes to participate.)

**Mid-Coast Spotlight** Dr. Michalakes said that she feels that it would be helpful to the Council to invite members of the public with different perspectives on palliative care to share their stories. Accordingly, she invited Jane Conrad to address the Council as a
consumer and advocate for palliative care. Jane’s husband, Ken Payment, was a patient of Dr. Michalakes’s. He died in 2017.

Jane Conrad shared that her husband had Parkinson’s disease for twenty years. They sought a referral to palliative care from Ken’s PCP when they knew Ken’s condition was deteriorating. They had three meetings with Dr. Michalakes over a period of six months, during which they were able to discuss Ken’s prognosis and what mattered most to him in the time remaining to him. It was extremely helpful to have this safe environment in which to discuss their fears and concerns about the progression of his disease, and how to handle possible episodes that might precipitate the end of his life. Dr. Michalakes and her nurse provided care and support to Jane and Ken as his condition progressed and he started receiving home hospice care in the fall. When Ken contracted pneumonia, he elected not to be treated, and entered the hospice house in Rockport, where he died. Jane’s gratitude for the palliative and end-of-life care Ken received is the inspiration for her work on community education on these issues and her desire to help others experience a comfortable and peaceful death surrounded by family in a supportive setting. She expressed an interest in helping Scott Fish and Kandyce Powell with public education and social media outreach. Kandyce stated that these personal stories speak volumes and they will follow up.

Meeting Dates for 2019:

January 25
April
September
November

Meeting adjourned.