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# Palliative Care and Quality of Life Advisory Council PL 2015, Chapter 203 2018 Annual Report

To

Health and Human Services Committee

By

Kandyce Powell, Executive Director

Maine Hospice Council, Inc.

On behalf of the

Palliative Care and Quality of Life Advisory Council

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Palliative Care and Quality of Life Advisory Council
PL 2015, Chapter 203
2018 Annual Report
To
Health and Human Services Committee
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Executive Director
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On behalf of the
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In 2018, the Palliative Care and Quality of Life Advisory Council, an inclusive group of knowledgeable, individuals representing various constituencies, held four all-day meetings, two conference calls and several sub-committee meetings, to continue addressing challenges preventing widespread implementation of palliative care in Maine. Even though the majority of patients and families who are living with serious illness would prefer staying at home, surrounded by friends and family, adequate resources are often not available nor accessible. Palliative care has been an emerging specialty for the past twenty years in the United States. However, the present health care model in the US has not kept pace, even though the data shows that palliative care is a cost-effective service, significantly enhancing a patient and family's quality of life.

Since Maine had no baseline data in 2015 when the law passed, the first three years of the Advisory Council were spent collecting information on the prevalence and structure of Palliative Care services in Maine. A discretionary proposal was submitted and awarded to the Maine Hospice Council for a market survey (attached). The results indicated only ten of thirty-four hospitals offered palliative care services of any kind. The information in the report, along with hours of input from organization representatives and experts in the field, was necessary for Council members to determine a strategic path forward. Follow are the four priority areas for the Council's 2019-2020 work plan.

Four sub-committees were convened, a) education, b) rural access, c) payer/provider, and d) pediatrics. Following are summaries from these committees.

#### **Pediatrics: Submitted by James Burns RN**

The Pediatric Palliative Care and Hospice work group convened a total of 5 times in 2018. It consists of membership from Maine Medical Center, Androscoggin Home HealthCare and Hospice, Core Health, as well as council representation from St Mary's Regional Medical Center and Northern Light Home Care and Hospice. The work group is drafting a proposal to submit to the Council for approval that will outline plans for statewide trainings based on the ELNEC (End of Life Nursing Education Consortium) curriculum for pediatrics. The location, timing and funding methods will be determined prior to the April 2019 meeting of the full advisory

council. The goal is to make the training a recurring offering which will be open to the entire state.

Education and Payer/Provider: submitted by Co-Chair Lauren Michalakes MD Educational initiatives proposed by the Palliative Care and Quality of Life Advisory Council (PCQOLAC) include a focus on both community and provider audiences. Certainly, one significant barrier to accessing palliative care in the State of Maine is a shortage of Board Certified physicians and nurse practitioners in this new field. In order to increase access of specialty-level palliative care knowledge and skills, the PCQOLAC entered into a collaboration with Maine Health to launch a State-wide learning community in Palliative Care utilizing the Project ECHO™ model.

Project ECHO (Extension for Community Healthcare Outcomes) is a collaborative model of medical education, which was created by Dr. Sanjeev Arora, of the University of New Mexico. Dr. Arora is a hepatologist who sought to improve access to Hepatitis C therapies to patients living in rural communities of New Mexico, by educating rural clinicians in the science and practice of evidence-based Hepatitis C treatments. The approach and methodologies have been duplicated and validated both internationally and nationally, as a way to share and "demonopolize" knowledge, through the development of learning loops and communities across vast regions and geographies. The outcome is that clinicians in rural and underserved areas are able to provide better care to more people, right where they live. Evidence is evolving that outcomes achieved through these learning communities can replicate those that are achieved in more urban, more populated medical centers. The model has been applied to a multitude of diseases, patient populations and clinical problems which lack clear access to appropriate care. In early 2018, members of the PCQOLAC learned about the applications of Project ECHO<sup>TM</sup>, and immediately recognized the opportunity here, in expanding palliative care language, skills and expertise across our state.

Although Maine Health serves as the host organization with the contractual relationship with Project ECHO<sup>TM</sup>, and has generously contributed technology and Program Management, this Palliative Care ECHO<sup>TM</sup> represents a true collaboration between the PCQOLAC, palliative care programs, primary care practices, educational entities and other providers and clinicians across the State.

Project ECHO<sup>TM</sup> is a telehealth powered educational template utilizing ZOOM technology to link "hub" centers of expertise with "spokes" in primary care and rural settings, seeking information and knowledge. The format is monthly hour-long scheduled sessions, composed of short didactic presentations presented by faculty on core topics, followed by actual case discussions brought forward by participants in spoke sites. Much of 2018 was spent developing relationships, laying the groundwork, and educating our stakeholders. Early 2019 has actually seen the launching of our first ECHO clinics in Palliative Care. In our February ECHO, we had 41 clinicians on video, from across Maine Health, Northern Light Health, Central Maine Healthcare, St. Mary's Health, Androscoggin Home Health and Hospice, educational entities, and members of our FQHC communities. Thus far, we have had excellent feedback from "spokes." We are sensing growing energy, and anticipate even greater participation moving forward, as we evolve into a successful State-wide learning community in Palliative Care.

Palliative Care is interdisciplinary team-based care, with a goal to maximize quality of life for patients and families living with serious medical illness. Quality-based palliative care involves multiple disciplines, including physicians, nurse practitioners, nurses, social workers and chaplains. When integrated early into the care of patients with serious illness, outcomes result in better quality of life, less aggressive futile care, greater utilization of hospice care, with less resources spent. Palliative care is not the same as hospice care in this context. While hospice is typically appropriate for patients with a prognosis of 6 months or less, palliative care can be delivered anytime across the trajectory of a serious illness, at any age. It may, and should be delivered in parallel, and in addition to those treatments that are disease-specific and life-prolonging.

A significant barrier to the growth of palliative care program, with assured access to palliative care for all patients in need, is the fact there is no reliable and sustainable reimbursement for this specialized type of care. While hospice care is funded through the Medicare Hospice Benefit, which includes care for, physician oversight, nursing case management, social work, chaplain medications, medical equipment, and other in-home supports, there is no equivalent program reimbursement for palliative care.

In recent years, there has been a growing interest in provide-payer relationships in the palliative care world of evidence and innovation. Palliative care can provide higher quality care, at a diminished cost. Sometimes people live longer. Palliative care is not lesser care. It is not taking care away. It is different care. It aligns what patients want with what's achievable, based on the realities of the illness.

Today's reimbursement for palliative care delivery is not adequate, in that it fails to reward the contributions of non-provider team members. Payment is under traditional Part B, for interventions and care provided by physicians and nurse practitioners. It does not reimburse for social work, chaplains, therapists, interdisciplinary discussion time, or 24/7 support.

Nationally, our leadership and stakeholder organizations have seen the need to find ways to align reimbursement with the way this work is optimally delivered. This has led to introduction of alternative payment models to CMS, which are apparently ready for National pilots. One has been proposed by the AAHPM (The American Academy of Hospice and Palliative Medicine), the other by C-TAC (The Coalition to Transform Advanced Care). Both are home-based palliative care models, and are focused on clarifying goals of care, delivering pain management, and providing ongoing relationships that help patients meet their goals as clinical issues arise.

The PCQOLAC is interested in exploring the development of home-based delivery models of palliative care. There is evidence that, when implemented, these programs do provide outcomes that are meaningful to patients, families, providers and payers.

A small committee has organized and gathered to discuss the possibility of a small pilot. We've identified that while there are areas of the State with well-developed hospital-based programs, there have been few efforts to grow programs that are predominantly community or home-based. The committee is exploring the possibility of one regional program in Coastal-rural Maine (Coastal Healthcare Alliance) to work with a payer (Community Health Options) to identify

patients in need of palliative care, and match them with a referral to a series of community-based intervention, including NP visits, social worker visits, interdisciplinary discussions, and telehealth virtual visits.

Over the next few months, we hope to clarify and develop the working relationship between our two organizations. The first phase will focus on developing processes that result in best outcomes for patients and families, as this small coastal program develops. We hope to document these outcomes, initially in an observational fashion. As the initiative evolves, we hope to be able to expand the concept to more patients, more providers, and use the data to support an alternative model for reimbursement that aligns with what other National initiatives have demonstrated.

#### Rural Outreach: submitted by James VanKirk MD

The Advisory Council is concerned about the lack of access to quality Hospice and Palliative Care services in large areas of Maine. While the population in these areas is limited, there are several geographic regions, including the off-shore islands, with little or no service. The Council is interested in pursuing new collaborative approaches to care in order to reach these populations, but realizes that many barriers currently exist. Many of these areas also lack broadband coverage, preventing the use of tele-health technology that would bring more services to a vulnerable population that is often unable to travel for care. We support the work by our national legislators to push the statewide spread of broadband access. We also recognize other barriers to the provision of tele-health services. Regulations often prohibit care or restrict payment for services. In addition, the proper credentialing that is required for providers across multiple service areas often prevents such care. Change needs to occur on several fronts.

#### Vacancies:

During the past year the Advisory Council was not able to obtain approval from legislative leadership to fill vacancies in a timely fashion. We had individuals with years of expertise in the field who were recommended for Council appointments. In the future, it is hoped these appointments can be made in a timely fashion, in order that the work of the Council can be as informed, thorough and expeditious as possible.

#### In Conclusion:

There are many barriers to statewide access to palliative care for all people, including inadequate broadband coverage; lack of reimbursement for palliative care service delivery at home; wide variability in institutional services; lack of fiscal prioritization; inadequate public and provider education, and lack of benefit coverage in Medicare, Maine Care and commercial insurance plans. The Palliative Care and Quality of Life Advisory Council takes its work seriously and looks forward to addressing the challenging health care issues continuing to face some of our most vulnerable populations.

## NEW FLORIDA REPORT ADVOCATES FOR PALLIATIVE CARE WITH COST-SAVINGS APPROACH

Florida TaxWatch released a report showing that increased access to palliative care doesn't just help patients, but also cut healthcare costs. The report distinguishes between hospice and palliative care and supports an expansion of community-based palliative care through various legislative proposals.

"Palliative care warrants special attention as a distinct and promising healthcare service," said Florida TaxWatch President and CEO Dominic Calabro. "With nearly one-half of American adults living with at least one serious condition or chronic illness, state policymakers should have a full understanding of how this could benefit all Floridians and take the expansion of palliative care under strong consideration."

One issue that often complicates the advancement of palliative care is a misperception about its purpose. "Palliative care cannot and should not replace hospice care," says Samira Beckwith, president and CEO of Hope Healthcare and the chairwoman of the Florida TaxWatch Center for Health and Aging. "The ideal interaction between palliative care and hospice is a seamless transition from palliative to hospice services."

The report suggest that the Legislature develop a regulatory framework for palliative care. "For the state to realize the cost-savings benefits of palliative care, the payment/reimbursement system must be addressed. To ensure the financial stability of palliative care providers, a system of care reimbursement that can be used by public and private payors must be developed, along with a definition of the services that constitute palliative care."

Florida TaxWatch promotes regulations that "balance the competing interests of protecting patients from being harmed by providers that do not have the expertise or capacity to provide appropriate and comprehensive palliative care services and avoiding overly burdensome regulations that will stifle growth and expansion." The group also advocates for increase raining opportunities, which they say are a major barrier to expansion of palliative care.

"To address this issue," they suggest, "the Legislature should fund increased palliative medicine fellowships, provide incentives for palliative care fellows to remain in Florida, invest in expanding training programs for nurses, and fund internship opportunities." (Florida Daily, 3/12, www.floridadaily.com/florida-taxwatch-increased-access-to-palliative-care-a-win-for-patients-while-cutting-healthcare-costs; Florida TaxWatch, 3/12, <a href="https://floridataxwatch.org/Research/Full-Library/ArtMID/34407/ArticleID/18688/Palliative-Care-in-Florida-Challenges-and-Options-for-Floridas-Future">https://floridataxwatch.org/Research/Full-Library/ArtMID/34407/ArticleID/18688/Palliative-Care-in-Florida-Challenges-and-Options-for-Floridas-Future</a>)

### Palliative Care and Quality of Life Advisory Council Roster March 2019

Council Member	Affiliation	<b>Contact Information</b>		
Myra Ross D.O. (Pending Approval)	Androscoggin Home Health and Hospice	15 Strawberry Lane Lewiston, ME 04240 myra.ross@androscoggin.org 207-777-7740		
Pamela Brown RN, CHPN	Togus - VA Maine Health Care System	16 Ryder Road Farmingdale, ME 04344 pamela.brown@va.gov (207) 689-1773		
James VanKirk MD	Northern Light Health Medical Director Eastern Maine Supportive Care Hospice of Eastern Maine EMHS Palliative Care Service Line	55 Carroll Court Brewer, ME 04412 jvankirk@northernlight.org 207-852-4585		
James "Greg" Burns	Clinical Manager Pediatrics/Maternal Health Palliative Care Coordinator	burnsgre@gmail.com 207-415-4791		
Kolawole Bankole MD, MS, MBA	Director/Administrator Local Health Officer PPH and HS Dept.	Portland Public Health and Human Services 389 Congress Street Portland, ME 04101 bak@portlandmaine.gov (cell) 207-319-2102, (w) 207-756- 8054		
Lauren Michalakes MD	Coastal Healthcare Alliance Medical Director of Hospice and Palliative Care Program	Pen Bay Medical Center 6 Glen Cove Drive Rockport, ME 04856 <a href="mailto:lmichalake@wcgh.org">lmichalake@wcgh.org</a> <a href="lmichalakes@gmail.com">lmichalakes@gmail.com</a> 207-691-0343		
Steven D'Amato BScPharm (Pending Approval)	Executive Director New England Cancer Specialists	100 Campus Drive, Ste 108 Scarborough, ME 04074 damats@newecs.org 207-303-3330 207-232-8010		
Council Member Kirsten Skorpen	Affiliation Palliative Care Social Worker	Contact Information 398 Barley Neck Road Woolwich, ME 04579 <u>kirstenskorpen@comcast.com</u> (207) 751-0499		

Kevin Lewis	CEO Community Health Options	Community Health Options P.O. Box 1211 Lewiston, ME 04243 klewis@healthoptions.org 207-402-3311
Dennis Fitzgibbons	Alpha One-(Retired)	46 Collins Road Yarmouth, ME 04096 fitz1of4@gmail.com 207-619-9229, (cell) 207-650- 8505
Terry Baker	American Cancer Society (Retired) Hospice Volunteer, Androscoggin Home Health & Hospice	24 Columbia Ave. Brunswick, ME 04011 terry.baker819@yahoo.com
Elizabeth Keene	VP, Mission Integration St. Mary's Health System	St. Mary's Health System 96 Campus Ave #321 Lewiston, Me. 04240 ekeene@stmarysmaine.com 207-777-8805
		20 Madison Ave.
Bill Primmerman (Pending Approval)	Community Health Educator, Somerset Public Health	Skowhegan, Me. 04976 <u>bprimmerman@rfgh.net</u> 207-858-8450
Kandyce Powell	Maine Hospice Council	P.O. Box 2239 Augusta, ME 04438 kpowell@mainehospicecouncil .org 207-626-0651

## 22nd Maine Pain Symposium

## "Balancing Pain Management With The Opioid Crisis: Are We Making Progress?"



Maine Hospice Council and Center for End-of-Life Care Where Change Happens

Featuring:

**Keynote Speaker** 



Robert Twillman, PhD, FACLP Kansas University School of Medi-



Steve D'Amato, RPh, BSPharm Executive Director, New England Cancer Specialists



Tamara King, Associate Professor, UNE College of Osteopathic Med.



Johanna Buzzell, information, Data Systems Manager and PMP coordinator for Maine

UNE - Biddeford Campus - Multi Purpose Room

May 1, 2019 - 8:00AM-4:30PM

Welcome: Jane Carriero, Dean, College of Osteopathic Medicine

Keynote: Robert Twillman, PhD, FACLP

Dr. Twillman has over 25 years experience in the field of pain management. Formerly the Executive Director at the Academy of Integrative Pain Management. Dr. Twillman is also a Clinical Associate Professor of Psychiatry and Behavioral Sciences at the University of Kansas.

After Dr. Twillman's presentation, participants will be able to:

- Describe the importance of attending to pain, opioid use disorder, and other mental health conditions in order to address the opioid crisis
- Describe the integrative model of pain care and its importance in resolving the opioid crisis
- List barriers preventing widespread adoption of the integrative model of pain care

Along with the spotlight speakers:, the event will also feature "Challenges to Access: Interdisciplinary Panel Discussion ": Zoe Tenney, Northern Light Palliative Care; Bonita L Pothier, Regional Representative, US Senator Angus King; Myra Ross DO, Hospice and Palliative Care Physician, Androscoggin Home Health and Hospice; Pam Brown, VA Hospice and PC Coordinator; and Greg Marley, Clinical Director, NAMI Maine.

> For more information or to register: Call (207) 626-0651 UNE's multi-purpose room is handicap accessible

Thank You to Our Generous Sponsors!

Drs. James & Tricia VanKirk



NEW ENGLAND Cancer Specialists



This activity has been planned and implemented in accordance with the Essentials and Standards of the Maine Medical Association Committee on Continuing Medical Education and Accreditation through the partnership of Maine Medical Education Trust and [insert name of non-accredited sponsor]. The Maine Medical Education Trust is accredited by the Maine Medical Association to provide CME activities for physicians.



The Maine Hospice Council is accredited by the Accreditation Council for Pharmacy Education as a provider of continuing pharmacy education.

This continuing nursing education activity was approved by the Northeast Multistate Division, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.



## Maine Hospice Council and Center for End-of-Life Care Upcoming Events



April 16th, 2019

Quarterly Education Meeting - "Suicide Prevention Gatekeeper Training"

Viles Estate, Augusta

9:00am - 1:00pm

Next meetings: July 8th, "Literacy Issues"; Oct. 7th, "Preparing for Approaching Death"



May 1, 2019 22nd Annual Maine Pain Symposium UNE Biddeford Campus Multi Purpose Room 8:00am - 4:30pm



October 18, 2019
National Hospice Volunteer Conference
Holiday Inn by the Bay, Portland
8:00am -4:30pm



October 25-27, 2019 Annual Wellness Retreat Rangeley Inn, Rangeley



November (TBA), 2019 Blaine House Tea Blaine House, Augusta

If you are interested in a particular topic for an event, please contact us today.

For more information, please call us at (207) 626-0651 Email: krandall@mainehospicecouncil.org or visit www.mainehospicecouncil.org

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JUNE 16, 2015

PUBLIC LAW

#### STATE OF MAINE

# IN THE YEAR OF OUR LORD TWO THOUSAND AND FIFTEEN

S.P. 280 - L.D. 782

An Act To Improve the Quality of Life of Persons with Serious Illnesses

Be it enacted by the People of the State of Maine as follows:

Sec. 1. 5 MRSA §12004-I, sub-§47-I is enacted to read:

47-I.

Human Services

Palliative Care and E

Expenses Only

22 MRSA §1726

Quality of Life
Interdisciplinary
Advisory Council

Sec. 2. 22 MRSA §1726 is enacted to read:

#### §1726. Palliative Care and Quality of Life Interdisciplinary Advisory Council

The Palliative Care and Quality of Life Interdisciplinary Advisory Council, as established in Title 5, section 12004-I, subsection 47-I and referred to in this section as "the advisory council," is established to improve the quality and delivery of patient-centered and family-focused care in accordance with this section.

- 1. Definitions. As used in this section, unless the context otherwise indicates, the following terms have the following meanings.
  - A. "Palliative care" mean's patient-centered and family-focused medical care that optimizes quality of life by anticipating, preventing and treating suffering caused by a medical illness or a physical injury or condition that substantially affects a patient's quality of life, including, but not limited to, addressing physical, emotional, social and spiritual needs; facilitating patient autonomy and choice of care; providing access to information; discussing the patient's goals for treatment and treatment options, including, when appropriate, hospice care; and managing pain and symptoms comprehensively.

- B. "Serious illness" means a medical illness or physical injury or condition that substantially affects quality of life for more than a short period of time. "Serious illness" includes, but is not limited to, Alzheimer's disease and related dementias, lung disease, cancer and heart, renal or liver failure.
- 2. Membership. The advisory council consists of the following members:
- A. Five persons with experience and expertise in palliative care in acute hospital care, long-term care, in-home care and hospice care with respect to pediatric, youth, adult and elderly populations as follows:
  - (1) Two persons appointed by the Governor. One person must be a physician who is certified by a national board of hospice and palliative medicine. One person must be a registered nurse or advanced practice registered nurse who is certified by a national board for certification of hospice and palliative nurses; and
  - (2) Three persons appointed by the executive director of the Maine Hospice Council, established in section 8611, who are health professionals with palliative care work experience or expertise in the delivery of palliative care;
- B. Two persons appointed by the President of the Senate. One person must be a licensed pharmacist with experience working with persons with serious illnesses. One person must represent hospitals in the State;
- C. Two persons appointed by the Speaker of the House of Representatives. One person must be a licensed social worker with experience working with persons with serious illnesses and their family members. One person must represent health insurers;
- D. Two persons appointed by the member of the Senate who is the leader of the minority party in the Senate. Both persons must represent statewide organizations that advocate on behalf of persons with serious illnesses;
- E. Two persons appointed by the member of the House of Representatives who is the leader of the minority party in the House. One person must be a spiritual counselor with experience working with persons with serious illnesses and their family members. One person must represent persons 55 years of age and older; and
- F. The executive director of the Maine Hospice Council, established in section 8611, who serves as a nonvoting member.
- 3. Terms; vacancies; expense reimbursement. A person appointed to the advisory council serves a 3-year term, subject to termination by decision of the appointing authority. When a vacancy occurs, the appointing authority shall appoint a new member to serve for 3 years. As provided in Title 5, section 12004-I, subsection 47-I, members serve on a voluntary basis, are not eligible for payment for their service and may be reimbursed for necessary expenses.
- 4. Conduct of business. At the first meeting of the advisory council and annually thereafter, the members shall elect from the membership a chair and a vice-chair and shall determine their duties. The chair and vice-chair shall call at least 2 meetings per year and other meetings as requested by a majority of the membership or as determined by the chair and vice-chair. A majority of the membership constitutes a quorum. All meetings of

the advisory council are public proceedings, are open to the public and must be held in locations that are convenient for public access and that are provided by the Maine Hospice Council, established in section 8611. As appropriate to the agenda for the meeting and in conformance with the Maine Administrative Procedure Act, all meetings must provide an opportunity for public comment.

#### 5. Duties. The advisory council shall:

- A. Consult with and advise the Maine Center for Disease Control and Prevention on matters related to the establishment, maintenance, operation and evaluation of palliative care initiatives in the State:
- B. Analyze palliative care being provided in the State;
- C. Make recommendations to improve palliative care and the quality of life of persons with serious illnesses; and
- D. Submit a report to the joint standing committees of the Legislature having jurisdiction over appropriations and financial affairs, health and human services matters and insurance and financial services matters by January 1st each year providing the findings and recommendations of the advisory council.
- 6. Funding. The advisory council may accept funding that is not public funding.

#### Sec. 3. 22 MRSA §8615 is enacted to read:

#### §8615. Palliative care initiatives

To the extent allowed by available resources, the council shall establish a palliative care consumer and professional information and education program to maximize the effectiveness of palliative care initiatives by ensuring that comprehensive and accurate information and education are available to the public, health care providers and health care facilities. The council shall publish and maintain on a publicly accessible website information and resources related to palliative care, including, but not limited to, links to external resources, continuing professional education opportunities, delivery of palliative care in the home and in primary, secondary and tertiary care environments, best practices for palliative care delivery and consumer educational materials and referral information for palliative care, including hospice care. The council may develop and implement other initiatives regarding palliative care services and education as it determines to be appropriate. The council may seek and accept funding to cover the costs of the Palliative Care and Quality of Life Interdisciplinary Advisory Council under section 1726. In performing its work under this section, the council shall consult with the Palliative Care and Quality of Life Interdisciplinary Advisory Council.

Sec. 4. Palliative Care and Quality of Life Interdisciplinary Advisory Council. Appointments to the Palliative Care and Quality of Life Interdisciplinary Advisory Council required by this Act must be made no later than 90 days after the effective date of this Act. Notwithstanding the Maine Revised Statutes, Title 22, section 1726, subsection 3, each appointing authority, when making initial appointments under Title 22, section 1726, subsection 2, paragraphs B to D, shall appoint one person for a 2-year term and one person for a 3-year term. When all appointments have been made, the

executive director of the Maine Hospice Council, established in Title 22, section 8611, shall call and convene the first meeting of the advisory council. The first meeting of the advisory council must be held no later than October 1, 2015.

#### CITIZENS TO IMPROVE END-OF-LIFE CARE

#### End-of-Life Care Statute, 120th Maine State Legislature

Title 24-A, Sections 2759, 2847-J, and 4249: Hospice care, palliative care and end-of-life care

#### **Definitions**

"Hospice care services" means services provided on a 24-hours-a-day, 7-days-a-week basis to a person who is terminally ill and that person's family. "Hospice care services" include, but are not limited to, physician services; nursing care; respite care; medical and social work services; counseling services; nutritional counseling; pain and symptom management; medical supplies and durable medical equipment; occupational, physical or speech therapies; volunteer services; home health care services; and bereavement services.

"Person who is terminally ill" means a person who has a medical prognosis that the person's life expectancy is 12 months or less if the illness runs its normal course.

#### **Insurance Coverage**

Coverage for hospice care services. All individual health policies, all group insurance policies and contracts, and all health maintenance organization individual and group health contracts must provide coverage for hospice care services to a person who is terminally ill. Hospice care services must be provided according to a written care delivery plan developed by a hospice care provider and the recipient of hospice care services. Coverage for hospice care services must be provided whether the services are provided in a home setting or an inpatient setting.

Application: The requirements of this Part apply to all policies, contracts and certificates executed, delivered, issued for delivery, continued or renewed in this State on or after January 1, 2002. For purposes of this Part, all contracts are deemed to be renewed no later than the next yearly anniversary of the contract date.

Exemption from Review: Notwithstanding the Maine Revised Statutes, Title 24-A, section 2752, this Part is enacted without review and evaluation by the Bureau of Insurance within the Department of Professional and Financial Regulation.

#### Maine Center for End-of-Life Care

The Department of Human Services Bureau of Health may establish, through contract or otherwise, the Maine Center for End-of-Life Care. The purpose of the Center is to educate health care providers and the public regarding pain management and palliative and end-of-life care. The Center must maintain a registry of health professionals trained in pain management and palliative and end-of-life care. The Bureau shall solicit and accept outside funding through grants and other sources to establish and operate the Center, which must be hosted by an educational institution, professional association or other entity interested in the care of the terminally ill. By January 15th each year the Bureau shall report to the joint standing committee of the Legislature having jurisdiction over health and human services matters regarding the operation of the Center and its funding.

The Center shall undertake a study of end-of-life and palliative care, pain management and barriers to the establishment of inpatient hospice programs in the State. The study must include recommendations for overcoming those barriers and a strategic plan for providing end-of-life and palliative care statewide and consider other issues as determined by the Center.

Appropriation for Center for End-of-Life Care: \$500,00 (allocates funds to establish the Maine Center for End-of-Life Care through outside grants and other sources of funds)

#### Professional Education

The Department of Professional and Financial Regulation, Office of Licensing and Registration shall provide a report on current professional entry-level and continuing educational requirements related to end-of-life care for the following licensed professions: counselors, social workers, psychologists, allopathic medicine, osteopathic medicine, nursing, funeral directors, acupuncturists and naturopathy. For the purposes of this report, "end-of-life care" includes palliative care, hospice, pain management, advanced health care directives, appointment of health care decision surrogates and do-not-resuscitate orders. The office shall request the licensing boards for the professions listed in this section to provide a statement assessing how current entry-level and continuing education requirements address end-of-life care issues. The office shall submit these statements in the form of a report to the Joint Standing Committee on Health and Human Services by January 15, 2002.

Appropriation for Study: \$7,400.00 (allocates funds for the per diem, travel, advertising and other costs associated with conducting a study of end-of-life related educational requirements for professionals

working in end-of-life care)

#### Baseline Data and Standardized Assessment Tools

The Maine Health Data Organization, referred to in this section as the "organization", established in the Maine Revised Statutes, Title 22, chapter 1683, shall direct an effort to gather baseline data and standardized assessment tools regarding end-of-life care within the organization's present database. This data may include information regarding end-of-life care, palliative care, pain and symptom management and quality indicators for the care of terminally ill persons.

#### Funding for Volunteer Hospice Programs

Maine Hospice Council

Provides funds to support volunteer hospice programs

Appropriated: \$50,000.00 (FY 2001-02)

#### Medicaid Reimbursement for Hospice Care

By April 1, 2002, the Department of Human Services shall adopt rules increasing the reimbursement for hospice care for routine home care to provide for reimbursement at the level paid under the Medicare program plus an additional 23 percent. Rules adopted pursuant to this section are routine technical rules as defined in the Maine Revised Statutes, Title 5, chapter 375, subchapter II-A.

#### Appropriations:

FY 2001-02 FY 2002-03

state \$133,159 state \$186,750 federal \$263,917 federal \$372,046

These estimates are based on the assumption that approximately 348 individuals currently receiving home health services will shift to hospice; that approximately 32 individuals in nursing homes will receive hospice services; and that 26 home and community-based participants will receive hospice services. These estimates are also based on an average length of stay of 50 days. The cost of this measure may be higher or lower depending on actual experience.

The Department of Human Services will incur some minor additional costs to conduct an annual cost-benefit analysis to determine savings generated by implementing this measure. These costs can be absorbed within the department's existing budgeted resources.