Representative Poliquin, Representative Rosen and Members of the Congressional Task Force on Palliative Care, thank you so much for recognizing the importance of palliative care by forming this task force. I am Dr. Lauren Michalakes from Rockport, Maine, and I am pleased to share with you my observations as a physician with many years of experience in the field of hospice and palliative care and a member of Maine’s own Palliative Care and Quality of Life Interdisciplinary Advisory Council.

In 2015 Maine became one of the many states to pass legislation that resulted in the creation of a Palliative Care and Quality of Life Interdisciplinary Advisory Council. This followed activity started in 2013, with model legislation crafted by the American Cancer Society’s Cancer Action Network. We, members of the Advisory Council, were named by various members of State government. We are providers, advocates and stakeholders. We represent our respective geographic regions, and our professional disciplines. As defined by the statute, our goal is to assess the status of palliative care in the state of Maine, make recommendations back to the joint standing committees, and participate in initiatives that will result in improvements in the care and experience of patients and families living with serious and life-limiting illness.

I would like to share with you what we have learned through our work in the Advisory Council.

Based on a survey we completed in 2016, we learned that only 29% of our hospitals (10/34) reported having some type of palliative care available to hospitalized patients. These hospitals are more likely to be in our more populated areas, like Portland, Lewiston and Bangor, while leaving vast rural regions of the state with absolutely no access to hospital-based palliative care. Only 8 of these 10 programs were billing for physician-derived palliative care services.

26% of our hospice programs (7/26) reported having in-home palliative care programs. 57% of these programs were dual licensed home health and hospice agencies that were providing hospice-like services to traditional home-health patients, utilizing only the Medicare Home Health Skilled Benefit, as
reimbursement. This implies that no additional revenue was provided to the agency, in spite of adding additional supports or services.

We have learned that there is no consistency with regard to these palliative care programs. Some programs are single physicians working alone. Some are nursing driven. Many lack dedicated participation of other disciplines, such as social workers and chaplains. Some programs were predominantly nursing and social work driven. This implies that some programs lack adequate interdisciplinary representation and function, with is at the core of a high quality palliative care, consistent with national standards.

We have spent time exploring the barriers to building palliative care programs. As a new field in medicine, palliative care certainly suffers from lack of awareness, lack of understanding of what “it” is, and how it differs from and relates to hospice. There is also a workforce issue, in that we lack adequate numbers of physicians, nurses and social workers, who have appropriate training and credentials to do this work. Planned initiatives for the upcoming year, therefore, include undertaking an educational campaign using social media to increase public awareness regarding the definitions and value of palliative care. And to promote provider education, we are collaborating with hospital systems to create a state-wide learning community, utilizing the teleconferencing platform, which originated at the University of New Mexico, Project ECHO™ (Extension for Community Healthcare Outcomes).

By far, the most important message I have for you today, is that the biggest barrier to expanding access to palliative care is the fact that it is not paid for. For years, we have made excuses for low utilization of palliative care. Patients might not understand it. They might not want it. The same for physicians. But the biggest reason we have low utilization of palliative care is that we have not yet built it. And the reason we have not built it, is because there is no reliable and sustainable method of reimbursement.

Palliative care is high intensity team-based care. It was born in the late 1990s and early 2000s, at a time when fee-for-service was the predominant method of reimbursement, for which palliative care is not a good fit. There are no technical and easily billable procedures in palliative care. The 3 most commonly used tools in our toolkit are communication, relationship building and time, which is often a challenge under the present system of coding for evaluation and management services for medical billing.

In spite of that, some of our clinical and research leaders in our field have been able to demonstrate the value of this type of care.

Such that, we now know, palliative Care, when integrated early - as standard of care- for those with serious and life-limiting illness – the results are reproducible. Patients report an in improved quality of life. There are less emergency department visits, less hospital and ICU days. Patients receive less aggressive and futile treatments....They transition to hospice earlier. And they often live longer.

And after the death, families live on with healthier bereavements, experiencing less depression and guilt. And while not the initial goal, it turns out, palliative care can save money.
There is a growing body of evidence to support these statements. Let me share some examples.

1. The first study, which is classic now, was published in the NEJM in 2010, out of Massachusetts General and Dana Farber Cancer Institute. They compared early integration of palliative care into the care of half of their enrolled patients with advanced lung cancer. Half of the patients received standard oncology care, the other half received standard oncology care plus palliative care. Interestingly, these patients who received palliative care concurrent with their standard oncology care, enjoyed higher quality of life, better mood, less aggressive care and higher transitions to hospice. And they lived longer.

2. Another article is one published in JAMA Internal Medicine in June of 2018, which reported a meta-analysis of the economics of palliative care for hospitalized patients with serious illness. This was a comprehensive review of 6 previously published studies. The investigators reported an average of $3237 saved for each patient with serious illness, with some variation with regard to diagnosis. Further the introduction of palliative care did not seem to be significantly related to death during the hospitalization, as 92% of the patients examined were discharged alive.

Both of these articles are attached and available for your review.

So here we are in 2018. The future of healthcare payment is slowly arriving. We are hearing more, living more in a value-based delivery system. Yet we continue to be impacted by a world that is predominantly fee for service. My own health system, MaineHealth, was an early participant in the Medicare Shared Savings Program and a number of value-based contracts, yet because our hospitals continue to rely upon fee for service payments, they are challenged to invest appropriately in palliative care. It is the continued reliance on fee-for service that holds us back. This is in spite of us all knowing that value-based payments, or payment for healthcare that rewards quality and cost-effectiveness needs to be the solution to our survival, as a compassionate, fair, equitable, and affordable healthcare system.

Palliative care is the definition of value-based healthcare for patients with serious and life-illness. For patients with advanced cancer, congestive heart failure, chronic lung disease, for patients and families living with Alzheimer’s disease and dementia. Palliative care is the “Triple Aim.”

As described by Diane Meier, of CAPC, “By providing expert pain and symptom management, psychosocial supports and skilled communication with patients and families, palliative care can help ensure avoidance of unnecessary emergency department visits, hospital admissions, and unwanted procedures. Not only is unnecessary cost reduced, but palliative care also improves the patient experience and facilitates informed choice.”
How does this work? When people are facing life limiting illness, there is a tendency to assume they lose all hope, they will fight until the end, and they will take any treatments offered. But it turns out, when people more fully understand their illnesses, understand their likely trajectories and their prognosis, they can make better decisions for themselves. They often choose comfort and home, over interventions and procedures that offer no value. I am often saddened when I see critically ill patients, wallowing on gurneys, waiting in hallways, for MRIs and PET scans, when we all know that time is short. The human condition is always capable of redefining hope, even in the face of serious and life-limiting illness. Even in the face of imminent death. In the experience of palliative care, hope is often for better time, not necessarily more time, if that “more” time is spent in debility and discomfort. Palliative care means that people are free to choose their path.

We are aware that our payers are an important partner in this work. We believe that innovative payment models must be developed in order for Palliative Care to become a reality for every citizen, every patient, every family member living with serious and life-limiting illness. Back in Maine we would welcome any opportunity to explore a payer-provider demonstration project, where we might be able to deliver the high value outcomes to a particular population or region. Initial conversations with several payers have taken place. We are also aware of at least 2 Alternative Payment Models that have been proposed to CMS, one by the AAHPM, the other by C-TAC. Both proposals deliver community-based palliative care for enrolled patients, and include interdisciplinary in-home supports, an emphasis on advance care planning, 24/7 availability to a clinician, and opportunities for sharing varying levels of risk, based on quality outcomes. We support and await the results of proposed demonstration projects.

On behalf of Maine’s Palliative Care and Quality of Life Interdisciplinary Advisory Council, I would like to extend my gratitude to Representatives Poliquin and Rosen, for hosting this Task Force, and allowing us to share our experiences, and I encourage Congress to push for improved payment for this evidence-based and patient-centered approach to meeting the needs of patients living with serious illness.