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**Statement for the Record on Behalf of the  
American Cancer Society Cancer Action Network**

**United States House of Representatives  
Energy and Commerce Committee  
Subcommittee on Health**

**Legislative Hearing: Examining Legislation to Improve Public Health**

**September 8, 2016**

The American Cancer Society Cancer Action Network (ACS CAN) would like to thank Chairman Upton, Ranking Member Pallone, Chairman Pitts, Ranking Member Green, and Members of the Energy and Commerce Health Subcommittee for holding a hearing on *Examining Legislation to Improve Public Health*, that includes H.R. 3119, the Palliative Care Hospice Education and Training Act (PCHETA). We would also like to thank Congressman Eliot Engel and Tom Reed for their leadership and commitment as lead sponsors to move this important legislation forward.

ACS CAN, the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. As the nation's leading advocate for public policies that are helping to defeat cancer, ACS CAN ensures that cancer patients, survivors, and their families have a voice in public policy matters at all levels of government.

During the 114<sup>th</sup> Congress, H.R. 3119 has garnered support from nearly 200 bi-partisan cosponsors in the House of Representatives, including over half of the full committee membership of the Energy and Commerce Committee. The legislation has also been endorsed by the Patient Quality of Life Coalition that was established in 2013 by ACS CAN, and has membership of over 40 patient, provider, and health system organizations.

H.R. 3119 would address three important public policy issues that have been identified as necessary to provide patients with serious illness better access to palliative care services throughout the continuum of their care: patient and provider education on palliative care as a delivery model of care for patients with serious illness; workforce development and training for health care providers on core competencies of palliative care; and expanded federal investment in palliative care research.

The goal of palliative care is to prevent and relieve suffering, and to support the best possible quality of life for patients and their families. Research suggests that palliative care should be made available to patients with serious illnesses upon diagnosis.<sup>1</sup>

Palliative care focuses on relief of the pain, symptoms, and stress of serious illness and on improving communication with patients and families. It is appropriate at any age and at any stage in a serious illness. Palliative care is provided by a team of providers that typically includes a palliative care doctor, nurse, social worker and a chaplain who work with the patient's other doctors to provide an extra layer of support for the patient and their family.

Evidence based research has concluded that patients with serious illness and their families receive poor-quality medical care that is characterized by inadequately treated symptoms, fragmented care, poor communication with health care providers, and enormous strains on family members or other caregivers.<sup>2,3</sup> By focusing on priorities that matter most to patients and their families, palliative care has been shown to improve both quality of care and quality of life for patients during and after treatment of a serious illness. In one study, patients with metastatic non-small-cell lung cancer who received palliative care services shortly after diagnosis enjoyed an improved quality of life compared to those who did not receive palliative care.<sup>4</sup> The American Heart Association / American Stroke Association have also stated that palliative care can be a helpful complement to current care practices and can improve quality of life for stroke patients, caregivers, and providers.<sup>5</sup>

Because their needs are met, patients receiving palliative care avoid crises, spend fewer days in the hospital, emergency department and intensive care unit, and have fewer re-admissions.<sup>6</sup> In fact, recent studies have demonstrated that high-quality palliative care not only improves quality of life and patient and family satisfaction, but it can also prolong survival.<sup>7,8,9</sup> Palliative care achieves these outcomes at a lower cost than usual by helping patients better understand their

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<sup>1</sup> Smith, TJ, Temin S, Alesi ER, Abernathy AP, Balboni TA, Basch EM, Ferrell BR, Loscalzo M, Meier DE, Paice JA, Peppercorn JM, Somerfield M, Stovall E, Von Roenn JH. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care Into Standard Oncology Care. *J Clinical Oncol* 2012; 30: 880-887.

<sup>2</sup> Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004 Jan 7; 291(1):88-93.

<sup>3</sup> Meier DE. Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care. *The Milbank Quarterly*. 2011;89(3):343-380. doi:10.1111/j.1468-0009.2011.00632.x.

<sup>4</sup> Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363:733-742.

<sup>5</sup> Palliative and End-of-Life Care in Stroke: A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association

<http://stroke.ahajournals.org/content/early/2014/03/27/STR.000000000000015> Mar 14.

<sup>6</sup> Meier DE. Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care. *The Milbank Quarterly*. 2011;89(3):343-380. doi:10.1111/j.1468-0009.2011.00632.x.

<sup>7</sup> Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363:733-742.

<sup>8</sup> Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC, Seville J, Hull JG, Li Z, Tosteson TD, Byock IR, Ahles TA Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA*. 2009 Aug 19; 302(7):741-9.

<sup>9</sup> Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki KJ Comparing hospice and non-hospice patient survival among patients who die within a three-year window. *Pain Symptom Manage*. 2007 Mar; 33(3):238-46.

needs, choose the most effective treatments and avoid unnecessary or unwanted hospitalizations and interventions.

In addition to important benefits to patient well-being and quality of life, palliative care has also been shown to reduce overall patient costs or to be cost neutral. One study of patients in Texas hospitals found that the provision of palliative care in the first 10 days after admission resulted in \$9,689 savings per patient for those who died in the hospital and \$2,696 savings per patient for those who were discharged alive.<sup>10</sup> A study of Medicaid patients in New York hospitals had similar findings, as the addition of palliative care resulted in \$6,900 savings per patient – \$7,563 per patient for those who died in the hospital and \$4,098 per patient discharged alive.<sup>11</sup> The cost savings associated with palliative care in this study were estimated to save the New York Medicaid program an estimated \$84-\$252 million per year.<sup>12</sup> A study of patients in hospitals across multiple states also showed a \$4,908 (\$374/day) savings per patient for those who die in hospital and \$1,696 (\$279/day) savings per patient for those who were discharged alive.<sup>13</sup>

ACS CAN strongly supports H.R. 3119. If enacted the legislation would improve the lives of patients with serious illness such as cancer, and provide patients greater access to palliative care services that have been proven to provide patients greater quality of life, and positive health outcomes. The legislation accomplishes this goal through three main public policy priorities:

#### *Patient and Provider Education*

Despite the proven benefits of patient access to palliative care, many patients with serious illness who could benefit are unaware of the existence of palliative care services, or incorrectly equate palliative care with end-of-life or hospice care. H.R. 3119 would direct the Agency for Healthcare Research and Quality (AHRQ) to establish a national campaign to inform patients with serious illness, their caregivers, and providers about the benefits of palliative care services throughout the continuum of their care. A broad based campaign is necessary to appropriately define palliative care as care for patients with any serious illness that is made available throughout the continuum of their care, encourage patients and families to seek high quality palliative care early in the course of illness, and educate healthcare professionals as to the appropriate role of palliative care in the care of their patients.

#### *Provider Education and Training Programs*

Provider education is a critical issue that must be addressed before greater patient access to palliative care services can be achieved. There is currently a shortage of palliative care trained doctors. Palliative medicine is a relatively new medical subspecialty, recognized by the American Board of Medical Specialties only 15 years ago. Also, due to the caps placed on Graduate Medical Education in the 1997 Balanced Budget Act, as a practical matter specialty training in palliative medicine is essentially entirely dependent on private sector philanthropy.

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<sup>10</sup> McCarthy IM, Robinson C, Huq S, Philastre M, Fine RL, Cost savings from palliative care teams and guidance for a financially viable palliative care program, *Health Serv Res.* 2015 Feb;50(1):217-36, Epub 2014 Jul 15.

<sup>11</sup> Morrison RS, Dietrich J, Ladwig S, Quill T, Sacco J, Tangeman J, Meier DE., Palliative care consultation teams cut hospital costs for Medicaid beneficiaries, *Health Aff (Millwood).* 2011 Mar;30(3):454-63.

<sup>12</sup> *Id.*

<sup>13</sup> Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, Meier DE, Cost savings associated with US hospital palliative care consultation programs, *Arch Intern Med.* 2008 Sep 8; 168(16):1783-90.

Thus, palliative care training is not Medicare funded, unlike all other medical training in the United States. There is a grave need to train doctors in the medical subspecialty, as well as train all health care providers in core competencies of palliative care including pain and symptom management, psychosocial assessment and communication.

H.R. 3119 would establish an education and training program modeled after the successful Geriatric Education and Training Programs that currently exist. If enacted, education and training programs would support palliative care curriculum development in medical schools, as well as training programs in palliative care for all key healthcare professionals required to provide palliative care – doctors, nurses, social workers and other health care professionals.

### *Research*

H.R. 3119 would also expand the federal investment in palliative care research at the National Institutes of Health (NIH). Historically, research focused on palliative care and symptom management has not been a priority across institutes at the NIH. A recent study found that less than one-one hundredth of one percent of the NIH budget is focused on improving quality of life in the setting of serious illness.<sup>14</sup> H.R. 3119 would address this important issue by requiring the Director of the NIH to develop and implement a strategy across all institutes within the NIH to expand and intensify research on palliative care and symptom management.

As the subcommittee examines ways that our current health care system can provide better quality, cost efficient care to patients with serious illness, we implore the subcommittee to closely examine the policy recommendations in H.R. 3119. On behalf of the millions of cancer patients, survivors and their families nationwide, thank you again to Chairman Upton, Ranking Member Pallone, Subcommittee Chairman Pitts, and Ranking Member Green for including H.R. 3119 in this important hearing on *Examining Legislation to Improve Public Health*. We look forward to continuing to work with the Energy and Commerce Committee to move this important legislation forward.

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<sup>14</sup> Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-Life*. Washington D.C.: Institute of Medicine, 2015, available at <http://nationalacademies.org/hmd/reports/2014/dying-in-america-improving-quality-and-honoring-individual-preferences-near-the-end-of-life.aspx>.